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THE MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES
SERVICE SYSTEM IN MINNESOTA

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CHAPTER ONE

INTRODUCTION TO THE STUDY

This chapter sets forth the purposes of the study, methodology, analytic framework, and the organization of the Report.

I. BACKGROUND AND PURPOSE

As Rothman¹ has amply documented, the United States throughout the 19th century developed geographically remote, custodial institutions for increasing numbers of categories of persons who were seen as "abnormal" – the mentally ill, the retarded, epileptic, blind, deaf, and others with serious physical/neurological impairments. It was assumed that such individuals had little potential for growth and independence and that, therefore, their needs were best met by isolation and protection from the insensitivity of the wider community.

Medical advances and psychological research in human development, combined with changing social attitudes toward those who are handicapped, have dramatically decreased the numbers of persons who are likely to be institutionalized for long periods because of a mental or physical disability.

Advocates for the deaf and blind, although not in agreement regarding the best service approaches, have been extremely successful in the past several decades in securing Federal and state commitments for the training and habilitation to independent living of persons with these physical impairments. Confinement of those whose only disorder is epilepsy is almost wholly a thing of the past due to the development of medications which effectively

1 Rothman, David. The Discovery of the Asylum.

control seizures for most persons. Similarly, the discovery of psychotropic drugs has revolutionized care and treatment of the mentally ill so that the likelihood of prolonged institutionalization has been drastically reduced, although community treatment and social rehabilitation services for the mentally ill – especially for the formerly institutionalized – has not kept pace with these developments. Indeed, the early experiences with deinstitutionalization of state psychiatric hospital patients into, e.g., domiciliary care with no supportive services, makes a point that must not be overlooked. "Deinstitutionalization" without appropriate follow-on care in the community may not improve the life of the client and may actually result in life circumstances inferior to those in a reasonably good institution.

In the past two decades the necessity of life-long institutional care of the mentally retarded has been subject to serious challenge by researchers, civil rights advocates, and parents of the retarded. Together, successfully established legal precedent² for the rights of these groups the retarded to education to develop their full potential. They have also had growing success in winning public acceptance of the view that the vast majority of mentally retarded people do in fact have the capacity to develop intellectually, socially, and emotionally, and that optimal development is most likely to occur in the least restrictive, more nearly normal living circumstances possible for the individual rather than in institutional settings.

"Institutional" care is characterized by large numbers of persons living in the same facility, a high degree of supervision and regimentation of personal activity, confinement to the same site for all or

2 Citations to be supplied

most activities and corresponding isolation from the non-disabled population. By contrast, community care or "normalization" requires the creation of a system of residential and support services which: (1) meets the needs of persons at all levels of disability; (2) fosters independence and opportunity for the development of individual potential; (3) represents the least restrictive residential alternative (e.g., own home with family, independent living arrangements, small group homes, nursing facilities) based on individual needs; and (4) prevents institutionalization and contributes to the expeditious return of the institutionalized individual to community living as nearly normal as possible. Such a system does not necessarily exclude institutional care, but would utilize institutions only as part of an array of responses to individual needs rather than as the routine choice of treatment for the retarded.

Advocates for the retarded have pressed for recognition of the "normalization" principle as a civil right which justifies a claim on public funds. The same arguments have been adopted by advocates for other mentally or neurologically disabled persons whose disabilities are present before age 18 -- the years in which most intellectual and physical development occur --and will impede independent functioning in adult life in the absence of special treatment and supportive services.

It was by this logic and constellation of advocacy groups that the concept of "developmental disability" was defined by the Federal Developmental Disabilities Act in 1970, as amended by P.L. 94-103, to include: disabilities of a person which are attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other condition found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning; or adaptive behavior

similar to that of a retarded person; or requires treatment and services similar to those required for such persons; or_ is attributable to dyslexia resulting from mental retardation (MR), cerebral palsy (CP), and other conditions noted above. Such disabilities must occur before age 18, can be expected to continue indefinitely, and must constitute a "substantial handicap" to a person's ability to function in society.

It is not surprising that the Developmental Disability (DD) concept as stated in the law is not well understood; the reference to impairment of "adaptive behavior similar to that of a retarded person", for example, is so broad and vague that almost anyone under 18 might be covered, depending upon the definition of "adaptive behavior"; inclusion of persons who require treatment services similar to those who are impaired in intellectual or adaptive functioning is equally a matter of interpretation. In brief, the language of the law makes it very difficult to determine who is and is not included and what treatment services are applicable. Certainly the law opens up possibilities for coverage of many more disability groups than states in fact cover.

In the face of such definitional confusion, "developmental disability" is frequently equated with a primary diagnosis of mental retardation, which includes retarded persons with or without cerebral palsy and other physical complications³. However, despite the problematic nature of the DD concept under the Developmental Disabilities Act, as amended, the Act clearly demonstrates the increasing affirmation of the principles and goals of deinstitutionalization and community care. These principles and goals

3 Because of this confusion, this Report refers to mental retardation/ developmental disabilities (MR/DP) programs through the text.

are further recognized and extended to all disabled persons under Title XX of the 1972 amendments to the Social Security Act and in the Education of All Handicapped Children Act of 1974.

Nevertheless, increasing acceptance of these principles and goals has not been sufficient to guarantee the efficient and expeditious implementation of reforms in service delivery systems at the state and local level. Federal and state funding has been inadequate, planning has frequently been haphazard and uncoordinated, and the specific objectives of an alternative system have been ill-defined. Even so, several states systematically initiated deinstitutionalization and the creation of community-based service systems for MR/DD persons prior to or shortly after these principles were enumerated in Federal law, and have achieved some measure of success in bringing about the desired system changes. Therefore, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the Department of Health, Education, and Welfare, contracted with Lewin and Associates, Inc. and the Human Services Research Institute to conduct a careful examination of mental retardation or, if possible, DD service systems in five of the states in which such systems are reputed to be relatively well-developed. The purpose of this effort is to synthesize and also capture in some detail the knowledge acquired by these states for the use of other states' policy-makers who seek to design and implement service delivery reform for the retarded and otherwise developmentally disabled citizens.

II. STUDY METHODOLOGY

A. State Selection Process

Since the maximum benefit of this study for other states is expected to come from identification of successful approaches to the complex process of creating a community-based MR/DD service system, an effort was made to identify those states which: (1) had at least three years implementation experience upon which to base conclusions; and (2) were reputed to have made significant progress in deinstitutionalization and the development of community-based care systems. Nominations were obtained from the major MR/DD constituency organizations and individual experts in the field, which yielded a cluster of states judged "good", with none frequently mentioned as "outstanding". In order to select among these states, it was decided to opt for maximum variation in the design of existing systems and for geographic dispersion to capture maximum variation in state political, social, and economic characteristics. The five states selected were: California, Connecticut, Georgia, Minnesota, and Pennsylvania. Of these states, only California and have explicit, broad coverage of non-retarded developmentally disabled persons.

B. Data Collection Procedure

A team of three Lewin and Associates/HSRI staff spent not less than five days in each state. During this time, interviews were conducted with state level agency officials with direct responsibilities for the MR/DD service system and those responsible for generic services; staff of appropriate legislative committees; governor's staff with responsibilities in this area; consumer organizations; and provider associations. These interviews were

designed to obtain information and competing perspectives on the history and current status of the state effort, including specifically the state's approach to eight key system elements (see Part III, Study Approach). Documents necessary to support judgments regarding each state's approaches and relevant data were also obtained on-site.

The study teams also visited two sub-state (regional and/or county) agencies with lead responsibilities in the service system, local generic resource agencies, and a variety of care settings for the developmentally disabled. This effort permitted the team to obtain a more detailed understanding of how the systems worked in practice. Supporting documentation and data were also obtained at the sub-state level.

C. Analysis

Data collected from each state were used to develop detailed descriptions of each state's approach to the creation of a MR/DD deinstitutionalization and community care system. The study team's perceptions of the factors affecting each state's approach and the implications of their choices for overall achievement of MR/DD service reforms were also made explicit.

These case studies served as the basis for comparative analysis of what approaches support and inhibit the orderly development of MR/DD service reform when variations in state political and social characteristics are taken into account.

Finally, unresolved issues identified through the five-state analyses, together with the study team's knowledge of Federal policy and program trends, were used as the basis for analysis of the factors which current and future efforts at state initiatives in this area must take into account.

D. Reliability and Validity

Since this study involved only five states, conventional statistical measures of reliability of data and construct validity were obviously out of the question. However, two procedures were used to satisfy the study team and the Federal Project Officer that the data obtained and analyses based upon them would advance the state of knowledge in this complex area. Specifically:

- Every state report was sent to that state's officials, constituency groups, and service providers for review and comment with respect to the accuracy, fairness of interpretation, and completeness of the state report.
- The entire report was submitted to an external review panel consisting of eight state executive and/or legislative staff in states without well developed MR/DD deinstitutionalization and community care systems. These reviewers were asked to comment on the appropriateness of the conceptual framework for analysis, the probable utility of the conclusions for state policy-makers, and the extent to which the conclusions are supported by the detailed discussion of each state surveyed.

III. STUDY APPROACH

A. Assumptions

This study takes as a given that the creation of community-based alternatives to larger institutional care for many of the retarded and other developmentally disabled persons is desirable/ it does not attempt to measure individual outcomes for persons in community vs. institutional care.

Furthermore, this study does not assume that there is one best way to design and implement a community-based care system for the MR/DD; the state-of-the-art in this area does not permit any such assumption.

Rather, fragmentary reports of state experience and the existing human services management literature suggest that eight generic elements of human services program design are important for successful initiation of an MR/DD service system. These eight elements were identified and each state's MR or DD service system has been described in relation to them.

In addition, certain specific aspects of each key system element were identified and assumed for purposes of this study to be important for effective performance. These aspects, referred to as study criteria, were used to guide the assessment of each state's approach to the eight key elements,

B. Key Elements and Study Criteria

The eight key elements in development of a community-based care system for the MR/DD are as follows:

_/ For a detailed rationale for deinstitutionalization, see V. Bradley, (get title).

- System organization. Determination of what units within state and sub-state levels of government are to be delegated responsibility for implementation of deinstitutionalization and the system of community-based care.
- Service coordination. The creation of mechanisms to ensure coordination of services down to the point of delivery of services to clients.
- Monitoring and evaluation. The creation of mechanisms to ensure that each unit performs its assigned responsibilities (i.e., is held accountable), and a systematic means for determining the effectiveness of the system in achieving desired objectives.
- Needs assessment. The determination of what services are needed by how many MR/DD persons.
- Resource inventory. The determination of what residential and supportive resources are currently available to meet identified needs.
- Planning and priority setting. The process by which funding/service gaps are identified and priorities are established for filling these gaps within a specified period of time.
- Coordinated funding. The identification of and arrangement for access to generic and special funding sources which can be utilized to implement plans.

- Resource development. The capacity to develop needed staff, facilities, and services to meet needs according to plans and priorities.

The sequence in which these key system elements have been presented is one which is logical and orderly. However, the necessity for this sequence of actions may or may not be demonstrated by an examination of actual practice; planning and priority setting may lead to, rather than evolve from, the establishment of an organizational structure for a MR/DD service system; coordination of funding may precede a precise measurement of needs, resources, and priorities; and so on. What is most important to bear in mind is that all of the key elements are interrelated.

Each key element and effectiveness criteria associated with it is described in the following pages.

1. System Organization a.

Study Criteria

Any mode of organization may be considered more likely to achieve system goals if it meets the following criteria:

- State MR/DD system objectives have been clearly specified.
- Overall responsibility for achievement of system objectives has been clearly assigned and there is a legislative/executive basis of authority with which to carry out this responsibility.

- Responsibility for key system elements, as defined in this study, has been assigned to specific units.
- Lines of authority are clear.

b. Rationale

If a MR/DD service system -- or, indeed, any human service system -- is to achieve its objectives, it is necessary that these objectives be clearly defined, that authority and responsibility for system performance be clear, and, responsibilities for all key elements within the system be explicitly identified and delegated to specific units at the state and/or sub-state level.

However, the creation of such a structure is particularly problematic in the case of MR/DD services for several reasons. First, establishment of clear agreement as to who is to be served to achieve what purposes is not simple to achieve. The nature of the population to be served -- the retarded? other DD groups? which ones? -- must be determined and can be a source of intense political controversy. Beyond this, there may be confusion regarding the relative emphasis to be placed on deinstitutionalization of those who are currently confined to institutions compared to prevention of institutionalization of MR/DD persons already in the community.

Second, regardless of the specific definition of the state's objectives, the creation of a community-based care system necessarily entails the participation of a multiplicity of resource agencies with differing Federal and/or state requirements.⁴ For example, agencies with resources and

⁴ While it is possible that a state with abundant resources could create and fund a MR/DD service program which could by itself directly provide for all the residential, medical, educational, social, and employment needs of the population to be served, it is highly unlikely that any state is in a position to do so. It is also contrary to a basic principle of the movement toward community-based care, i.e., integration of the MR/DD into the mainstream of the community as opposed to segregation in special services.

authority directly relevant to this population include Crippled Children's Services, State Departments of Mental Health or Mental Retardation, the Federal Social Security Agency (for SSI and Disability Insurance benefits), the State Developmental Disabilities Councils, the State Department or Bureau of Special Education, the State Vocational Rehabilitation Agency, etc. Agencies with authority and funds for generic supportive services include, e.g., the Title XX Social Services Agency, agencies or bureaus responsible for income maintenance, Medicaid, Food Stamps, housing, and transportation.

Ideally, these agencies and program resources would be delegated specific roles in a MR/DD service system. However, some agency must have overall responsibility for system performance, which in turn requires that such a lead agency have adequate statutory or regulatory authority to effectively ensure that delegated responsibilities are met. This may be difficult to achieve due to statutes governing locus of authority for control of other resources or to traditional interagency and state/local relationships.

Federal law requires that state governments exercise control over some programs relevant to the MR/DD, e.g., Vocational Rehabilitation, while other Federal programs mandate local control. Prime Sponsors control the bulk of CETA funds and metropolitan area control of housing funds; local autonomy and financial contributions with respect to Title XX social services and special education programs may vary greatly by state statute and long-standing traditions of state vs. county policy control. When local autonomy is the rule, the state may be faced with especially difficult problems in establishing authority for specific system actions; it may either delegate to counties over which it has little effective control, attempt

to create intermediate (regional) levels of government with greater state control, or pursue a variety of similar alternatives which may be counter to the state's political traditions -- and are therefore more difficult to achieve.

Finally, however the system is organized, if lines of authority are not clear and mutually understood, wasteful confusion and uneven access to services from one part of a state to another could occur.

2. Service Coordination

a. Study Criteria

Since any state deinstitutionalization and community care service system will involve more than one agency and/or level of government, coordination of efforts is required to some degree for each of the key elements discussed below. However, the creation of service coordination mechanisms down to the community level is highlighted here as a separate key element because of its centrality to achieving community-based care for a vulnerable population with multiple needs.

An effective state approach to this key element appears to minimally require the following if services to the MR/DD are to be coordinated at the point of delivery:

- The state has identified the range of resources which should be coordinated at the point of delivery and has communicated this information to the responsible local unit.

- The state has developed coordination agreements between state level agencies which administer/control resources.
- Local MR/DD agencies have identified resources and developed coordination agreements at the local level.
- There is provision for ongoing coordination of services for individuals through the case management function.

b. Rationale

The creation of service coordination mechanisms down to the point of delivery must take into account the problem of the extent of any agency's awareness of the full range of services which could and should be coordinated in behalf of the MR/DD. Comprehensive understanding of the proliferation of Federal, state, and local programs, each with its own requirements, which might be utilized for any human service system, has become a task beyond the grasp of most individuals at any level of government.

This suggests a need for ongoing, systematic effort at the state level to identify Federal and state program resources which could be used to serve the MR/DD population. Since many such resources are controlled to some degree by local agencies, it is especially important that local MR/DD agencies be informed of these resources and what they must do to bring about coordination of them for MR/DD clients.

The lead state MR/DD agency can facilitate coordination of services if it aggressively develops coordination agreements with other state agencies which control state and Federal resources; local MR/DD agencies will need to develop similar agreements with local bodies who control needed resources regardless of whether their source of support is Federal, state, or local.

In creating service coordination agreements, a state or locality is faced with many of the same issues involved in developing an overall organizational structure for the service system; agencies which control needed resources, either by law or political tradition, may be reluctant to relinquish some autonomy with respect to use of their "own" resources for their own service priorities.

This problem becomes still more difficult to overcome when Federal, state, or local program laws and regulations appear to exclude services to the MR/DD unless they meet other eligibility criteria. For example, the Federal Vocational Rehabilitation Program, which is administered by state governments, has been historically directed at a relatively brief duration of service for the adult, less disabled population. (Even though this program has been mandated for the past two years to include 35% "severely disabled" persons, state vocational rehabilitation officials have typically continued to construe their role as one which excludes most severely retarded and other DD persons.)

Finally, even if these requirements for service coordination are effectively met, this will not necessarily result in the coordination of services which are specifically tailored to the needs of the individual client. For the non-disabled population in need of a variety of income maintenance, medical, educational, employment, and social services, the "services coordination" issue has frequently been resolved in favor of providing one or more local agencies with information and referral responsibility, leaving to the client the task of applying for different benefits from a variety of Federal, state, and local agencies. No one "case manager" has overall responsibility and authority to secure the full range of needed

services for the client. This approach is generally held to be unsatisfactory for human services delivery (as demonstrated by increasing state efforts to create umbrella human resource agencies), but is especially inappropriate for meeting the needs of the MR/DD population, many of whom cannot act in their own behalf or are non-ambulatory. For this reason, it seems to be critically important that an MR/DD system provide for case managers at the local level who can and do act on behalf of clients to ensure that needed services are brought together for them from the time the client enters the system throughout the entire life cycle if services are still needed.

3. Monitoring and Evaluation

a. Study Criteria

To hold actors within the MR/DD system accountable for performance of agreed-upon roles and to assess adequacy of the system itself for meeting the objectives of the deinstitutionalization and community-based care effort may require that:

- Performance expectations for each unit/actor within the system are clear and measurable.
- Systems exist to monitor performance and compliance, and monitoring is conducted on a regular basis, with corrective actions taken as needed.
- Efficiency and effectiveness evaluations are routinely conducted and serve as the basis for system changes if indicated.

- Impact evaluations have been conducted or are planned for a specific future date, and are based on a clear definition of services in relation to client need when impact on clients is being evaluated.

b. Rationale

"Accountability" is a very popular term which simply means that those who are responsible for performance of specific roles within a system can be and are required to account for their performance or non-performance. In the absence of accountability, there can be no assurance that the objectives of a system will be met.

In order to achieve accountability, however, measurable performance standards must be developed for various actors within the system. A local unit cannot be held accountable for "stimulation of resource development", for example, in the absence of clear criteria for number or type of resources to be developed.

At the same time, the development of clear and measurable performance criteria is often technically difficult to accomplish. Translation of a mandate to "coordinate services required to meet individual needs" into measurable criteria presupposes that there is a clear notion of what types of services will meet what individual needs. State and local units may also inhibit the development of clear performance criteria for reasons ranging from a general resistance to being held accountable to a belief that over-specificity in performance expectations will stifle creativity and innovation in MR/DD system development.

No matter how well or poorly performance expectations have been stated, they will not serve to stimulate accountability if there is no system for monitoring performance on a regular basis and taking corrective actions if indicated. This requires at a minimum that state agencies prescribe simple and useful reporting forms and procedures – e.g., accounting procedures ~ for sub-state units with responsibility for MR/DD services if monitoring is to be accomplished.

Again, however, state agencies or local units may resist external controls, so that a lead agency will reduce its demands for information and frequency of monitoring rather than face the problems of securing interagency and inter-governmental responsiveness. Whether a monitoring agency will actually take corrective action depends on both the adequacy of its authority and the realistic political constraints it may face.

Evaluation includes periodic assessment of system-wide effectiveness in meeting goals and objectives; efficiency in utilization of resources; and impact, which may be defined as the effects (increased employability, personal skills, etc.) of the service system on individuals who have participated in it compared to similar persons who have not, or may more broadly address the effects of the presence of the system on community acceptance, awareness of the needs of MR/DD persons, and so on.

Effectiveness and efficiency evaluations may begin early in the system's development, inasmuch as trends in common design and implementation problems may become apparent through regular monitoring data if the state has the capacity to analyze and identify such trends. Major barriers to effectiveness and efficiency evaluation are the availability of good monitoring

data, as noted above, and the commitment of staff and/or resources to perform such analyses. When these barriers are not overcome, however, a community-based service effort will lack the ability to correct its systemic deficiencies and will thus run the risk of offering less than adequate and efficient services to the population it is intended to serve.

It should be noted that impact evaluations are costly and are most likely to be useful once the system is well-established, so that variation in results is less likely to be due to random variations in program implementation. In addition, however, impact evaluations of, e.g., the effects of the total community-based care effort on individuals, are extremely complex; if the state has not designed its community-based care services to meet specific needs of persons with differing levels of disability at different developmental stages, an impact evaluation can be extremely misleading to policy-makers.

4. Needs Assessment

a. Study Criteria

A systematic approach to assessing the needs of the MR/DD population, regardless of how it is organized in detail, would appear to minimally require the following:

- A clear definition of service/setting needs at different stages in the life cycle for persons with different levels and types of disability.

- Data gathering system has been developed to measure need as defined on statewide basis, taking into account services already provided to the MR/DD population.
- The data system permits prediction of potential demands of particular at-risk populations.
- Data is reported in consistent, useable form and analyzed by a unit identified as responsible for analysis.

b. Rationale

The development of information regarding the needs and characteristics of any population for whom services are to be provided is an important step in the planning, financing, and development of resources for a rational service system. In order for needs assessment to be meaningful, however, states must develop some general notions of service requirements for persons with different developmental disabilities and levels of functioning at different stages in the life cycle. In the absence of a working definition of appropriate service configurations, "need" will always be vague and boundless.

Completion of this initial step permits the state to develop a data gathering system which gives some sense of the total magnitude of the population which may over time come into contact with the public MR/DD system and thus supports planning and requests for funding and resource development activities. As the system progresses, however, needs assessment should become a more precise and sophisticated activity which concentrates on identifiable

risk populations (e.g., the middle aged retarded person living at home with older parents), utilizes trend data from other information systems (e.g., infant morbidity rates), and inspects service patterns and demand over the life of the program.

There are potential roadblocks to successful needs assessment as described here. To define needs in terms of services is a technically complex undertaking and the state-of-the-art is not well developed. Another major difficulty occurs in trying to secure uniformly accurate data on a statewide basis. Different state and local agencies which maintain data on size and characteristics of the MR/DD population may report different data items in non-comparable formats, and may fail to take services already provided into account in producing need estimates.

As with overall organization, it may be neither necessary nor desirable to create a separate needs assessment process as long as existing needs assessments conducted by various programs which come into contact with MR/DD persons are made sufficiently compatible to serve state community-based service program purposes. However, unless needs assessment data is adequately collected and ultimately channeled to some specified unit for regular analysis, it will not serve its important role in planning and performance of other key elements.

5. Resource Inventory a. Study Criteria

An inventory of resources currently or potentially available to serve the MR/DD, to be most effective, requires:

- A statewide resource inventory measure which is consistent with the state's service-based need definition.
- The inventory permits assessment of expansion capability, identifies limits on quality, and other characteristics of resources.
- The inventory includes identification of generic resources available to clients.
- The resource inventory is reported in a consistent format and data are routinely analyzed by a specified unit.

b. Rationale

Resource inventory is a key element which is integrally related to needs assessment and, by extension, to planning, resource development, and financing decisions. If states identify existing and potential residential and service resources in a manner which is consistent with the definitions of disability and need used in the needs assessment process, the two sets of data can easily be used to reveal resource gaps or imbalances which should be corrected by the community service system.

In addition to establishing the resource baseline on which the state must build, a resource inventory can help ensure maximum utilization of needed facilities and services by identifying under-utilization and can also assist consumers and local case managers in locating generic as well as specialized services for individual clients.

The inventory also enables the state to ascertain trends in the development of resources, to note regional differences in resource availability, and to assess service capacity in the private and public sectors alike. Repeated inventories should also indicate the extent to which service expansion goals have been realized.

Though a comprehensive inventory of resources can fulfill all of these expectations, there are several problems and pitfalls which may be anticipated. These are to a large extent comparable to those noted for needs assessment. There are the technical complexities of translating a "resource" into a service-based need framework and data maintained by different resource agencies may be non-comparable and insufficiently descriptive, particularly with respect to the nature and availability of generic program resources. These factors in turn make it difficult to develop a coherent resource data base which can be regularly analyzed for planning and other key elements.

6. Planning and Priority Setting

a. Study Criteria

Planning and priority setting to effectively support the MR/DD service system requires:

- The development of long-range strategic plans and priorities for system development.
- Clear criteria for the determination of short-term priorities, with specific milestones for serving each priority group.

- The development of mechanisms to secure inclusion of MR/DD priorities in other agency plans.
- Actual use of plans in determining the allocation of resources.

b. Rationale

While planning can subsume almost every activity associated with program development, this key element, in this context, refers to the difficult issue of deciding which MR/DD sub-groups, in what order, are to benefit from community-based services, if there are insufficient fiscal, residential, service, and/or staff resources to meet all the needs of this population at once.

The development of long-range strategic plans – e.g., how many persons are to be served by the end of a five-to-ten year period, at what cost, using what funding sources and modes of resources and services – is necessary to give the deinstitutionalization/community care effort continuity of direction. It is also a potentially powerful tool for maintaining the support of the executive and state legislatures for the continuation and growth of the system.

At the same time, orderly progression toward long-term goals requires that short-term priorities be established on the basis of explicit criteria (e.g., relative magnitude of need in relation to existing gaps in services, estimates of short-term capacity to develop appropriate resources, etc.). Specific plans with milestones for implementation may then be set and used to focus and assess system performance. However, since the resources

of a number of Federal, state, and local programs will be needed to implement even a modest plan, mechanisms must be created to secure the inclusion of MR/DD service priorities in these other agency plans.

Both the short and long range planning efforts should be used to guide requests for and actual allocation of funding, staffing, and other resources or the planning process or the MR/DD program itself may lose credibility in the eyes of all system participants.

It must be noted that, as is true of social program planning in general, the development of useful long-range plans is circumscribed by political and economic uncertainties and unforeseen changes in technologies for meeting specific population needs.

The development of short-term priorities and plans may be hampered by inadequate data as well as a widely-shared propensity to view planning as a process of incremental annual additions to the prior year plan rather than making more reasoned adjustments based on data and experience.

Among the barriers to inclusion of MR/DD service priorities in other agency plans and priorities, one is directly comparable to problems encountered in service coordination: different Federally funded, state, and local programs may be mandated to give priority to specific population groups, or may insist on determining their own priorities for service.

Also, the priority-setting and implementation planning cycles of individual programs differ, so that coordination of efforts to ensure consideration of the MR/DD population itself constitutes a major obstacle.

When a potential resource program with mandated target populations (e.g., minorities, the poor) is willing to include the MR/DD population and service priorities, it is faced with the administrative complexities of defining sub-groups of these persons who also meet other categorical program criteria.

Finally, the planning and priority-setting procedures of major resources, such as Title XX Social Services and public housing, are structured so that they require organized political effort by different groups to achieve priority status. Federal procedural requirements for Title XX plans, for example, actually create a political arena in which the needs of one group must be argued against another and elected officials must ultimately be responsive to the pressures placed upon them by different groups. The MR/DD population is often not effectively organized for this kind of effort and, indeed, the needs of one sub-group (e.g., the mentally retarded) may be pitted against another (e.g., the autistic), often with both losing out to more cohesive interests.

7. Coordinated Funding

a. Study Criteria

A state's approach to this most complex element would be considered optimal to the extent that:

- Levels of funding needed for MR/DD priorities are clearly specified on basis of rational criteria

- The full range of potential Federal, state, and local funding resources has been surveyed and binding arrangements for fund allocation have been made with agencies controlling these funds.
- Procedures for ensuring maximum utilization of individual entitlements have been developed and implemented.
- Procedures exist for packaging and disbursing multi-program funds to units responsible for services on a basis sufficiently simple and flexible to permit timely provision of services to meet individual client needs, and clients are not inappropriately placed due to funding constraints.
- The funding package available is consistent with MR/DD plans and priorities.

b. Rationale

This key element is somewhat comparable to organization and planning in that it encompasses the mobilization of the multiplicity of agencies directly or tangentially concerned with MR/DD clients. However, it is the development of a coordinated cross-program funding package to support the full range of community service efforts which is the most realistic available mechanism to ensure that such an effort can be initiated and continued.

A prerequisite for developing coordinated funding is the development by the lead MR/DD agency of clear criteria and justification for funding requests.

Next, binding agreements should be developed to make program funds available – by transfer, earmarking, or some other mechanism – for MR/DD purposes. Of course, coordinated funding would optimally occur in conjunction with the planning and service coordination processes. The achievement of inter-agency agreements to participate in the MR/DD service system can all too often be meaningless unless these commitments are accompanied by specific dollar commitments to support the effort.

Mechanisms to ensure full utilization of individual entitlements, such as Supplemental Security benefits for the disabled, are required for completely coordinated funding. If the state is to systematically ensure that funds will be available when and where they are needed, a funding strategy must be developed which can maximize utilization of entitlements and at the same time bring about the coordination of other Federal, state, and local resources with special MR/DD program funds to fill gaps.

Even coordination of funds from a variety of sources will not well serve the ultimate objective of making funds available to clients across a variety of settings unless there exists a simplified funding procedure for packaging and disbursing funds to the MR/DD service delivery level. Separate local applications to different resource agencies, with different funding cycles and procedures, and separate accounting requirements, could inhibit if not defeat the entire coordinated funding effort.

Finally, coordinated funding efforts should be tailored insofar as possible to MR/DD plans and priorities. In a world of scarce resources, it must be tempting to take whatever funds are available, even if they come with restrictions for their use which are inconsistent or even in conflict with the MR/DD plans and priorities in the short or long term. This is not an easy issue to resolve, but it cannot be avoided or funding sources will shape rather than support the system.

8. Resource Development

a. Study Criteria

The characteristics of a systematic approach to this key element include:

- Legislative or executive provision for start-up financing of small group and independent living situations which is made available in a timely, planned manner.
- Establishment of rate structures which do not discriminate against community care services for the MR/DD population and which adequately cover costs/salaries.
- Establishment and systematic implementation of training and technical assistance to build capacity to foster quality resources.
- Planned growth strategy for resources which is consistent with state MR/DD priorities.
- Establishment and implementation of mechanisms to overcome state institutional employee and community resistance to community care.
- Reduction of needless licensing barriers to providers while maintaining protection of clients.

b. Rationale

It cannot be assumed that the mere availability of resources to pay for care of the MR/DD will automatically result in the creation of needed facilities. Small providers in particular need capital to start their facilities (start-up financing).

Providers of all types may be deterred from entering the system due to rate structures (or salaries, in the case of state-operated facilities) which do not adequately cover costs and provide an acceptable return on investment/standard of living and may be non-competitive with rates/salaries offered under other programs for similar services (e.g., Title XX child care, juvenile justice foster care). An issue related to rates is the method of payment to providers adopted by a state. A charge-based fee-for-service approach to care of the MR/DD will have some advantages and disadvantages, while a per-diem payment system based on average costs per client has others; charge-based fee-for-service payments are more attractive to many providers because they generally promise full recovery of all expenses, but this method is complex to administer (itemized charges must be reviewed), and is subject to abuse unless carefully monitored; per-diem rates, depending on their adequacy, may require less ongoing justification by the provider and provide some financial cushion when lower-cost clients are present, and are administratively simpler. In either case, the effect of the payment mechanism on resource development will be heavily conditioned by the state's computation of allowable fees or per diem payments.

Since the community care movement is relatively new, it must be anticipated that systematic training of program administrators, providers, and individual provider staff will be necessary, as will provision of technical assistance to local units and providers regarding program administration and design.

A growth strategy for different types of community resources and for staff availability which is consistent with short and long range plans is also necessary to permit adequate preparation for resource development.

The state must also anticipate that, when state institutional employees are unionized and/or protected by civil service status, they will at best tie up funds for salaries and benefits which could be used for community resource development; at worst, they may actively oppose deinstitutionalization. The attitudes of local communities toward the presence of MR/DD persons in community residences and day programs must also be recognized as a factor which may affect the growth of community resources unless carefully and systematically handled by state and local MR/DD officials.

Finally, potential residential and other community service providers and individual staff will be reluctant to offer themselves as resources to the MR/DD system if they are required to pass through numerous physical safety, facility design, training, and other licensing requirements which serve no apparent purpose in terms of providing quality services to MR/DD clients.

The progress of resource development will thus be very much affected by a state's skill in reducing licensing "red tape" while maintaining protection of vulnerable clients.

While none of these criteria are simple to meet, there is considerable evidence even now that states will find state employee and community resistance to MR/DD system reform to be the most formidable barrier to resource development.

I. INTRODUCTION

This chapter presents an overview of the Mental Retardation/Developmental Disabilities (MR/DD) service system in Minnesota, a detailed description of how the state has approached the key system elements, an analysis of those actions and other factors which have contributed to strengths and weaknesses in the system, and the implications of Minnesota's approach for other states conducting or contemplating deinstitutionalization and community-based care for these populations.

In order to facilitate reader comprehension of the substance of this chapter, a glossary of terms, acronyms, etc. most of which are unique to Minnesota is provided as Appendix A.

A three-member study team spent a week in the State, with interviews and site visits to state officials and private advocacy groups in St. Paul; site visits to area/county officials and MR facilities in Rochester (the Southeast area economic planning center for the State); and comparable interviews and facility visits in the Twin Cities Metropolitan planning area. Specific contacts are listed in Appendix B.

II. SYSTEM OVERVIEW

Minnesota ranks 19th¹ among all states in population and 21st² in degree of urbanization, with 3.5% of the total population residing in SMSAs. There is significant internal variation in population concentration; of 87 counties, 19 are above and 68³ are below the average for the state, so that variations in resources and service delivery mechanisms would be expected and would constitute a significant social factor to be taken into account in the state's total approach, as well as the fact that Minnesota ranks 14th in geographical size.⁴ The per capita income in the state in 1970 was \$3,859, which ranked 17th in the nation.⁵ (The 1976 estimates show per capita income at \$6,153, with the state ranking 27th in the nation.)⁶ State tax revenues in 1976 were 2.2 M, ranking 12th in the nation.⁷

A. Overall System Design

Unlike other states surveyed, Minnesota's deinstitutionalization and community-based care system has emerged from a series of statutes and Executive Directives spanning two decades, as opposed to one unifying piece of legislation establishing an MR system. Comparable to most other states, however, the thrust of system development has been with respect to the mentally retarded rather than to the broader group of developmentally disabled persons as defined in Federal law. Thus, this chapter focuses on the MR service system, noting those points at which other DD persons are included.

1. Basic Organizational Structure

The dominant structural feature of the Minnesota system is that it is deliberately decentralized⁸ to Area Boards/Counties with respect to most of the decision-making and operational aspects of the state's approach to

deinstitutionalization and community care. The state-level role in system organization is best described as one of general policy direction, routine funding transfers, technical assistance, and integration of basic data for budget presentations. This overall organizational design is consistent with the state's history of county-level autonomy across all public endeavors. The actual structure assigns state and local roles in the following manner.

At the state level, the Department responsible for the MR/DD system is the Department of Public Welfare (DPW), an umbrella agency which includes a Bureau of Community Services (social services, e.g., Title XX, the MR Program Office, licensing and state grants-in-aid), a Bureau of Residential Services which administers the state MR and Psychiatric Hospitals, and a Bureau of Income Maintenance which administers AFDC, SSI, and Medicaid.

Education, Housing, Health, Transportation, Vocational Rehabilitation, and other relevant resources are located in separate departments. The Developmental Disabilities Council is entirely separate from DPW and is located in the Governor's State Planning Agency. The basic organization of DPW is shown in Exhibit 1.

While the Bureau of Residential Services exercises fairly direct supervision over the MR/Psychiatric hospital service system, state-level responsibility for deinstitutionalization policy and development of the community-based care system rests with the Bureau of Community Services and its constituent agencies -- the Division of Mental Retardation (DMR), whose role is essentially restricted to policy guidance; the Community Programs Division, which is responsible for funding Community Mental Health Area Boards and Day Activity Centers; and the Licensing Division. The major operational responsibility for DI and community care.

rests with 23 area mental health boards and the 87 county welfare departments included in each area.⁹ The Area Boards are responsible for overall planning and some direct clinical services for the MR, mentally ill, and chemically dependent (alcohol and drug abuse), with the counties in each area responsible for client intake and continuing case management. Each Area Board has an MR coordinator to take the lead on MR issues.

A variant on this basic structure which has been attempted, with limited success by the state, is to combine all human services planning functions under 13 human resources boards, corresponding to the state's 13 economic development regions. Under this mode, the area MH boards must coordinate with each other across a wider number of counties and programs, but front-line operational responsibility still rests with the counties. Only 4 Human Resources Boards are currently in operation, so that linkages between DPW and the community care system are essentially limited to a small state staff oversight of the 23 area boards and 87 counties, with no other meaningful mid-level supervisory or coordination mechanism.

The Developmental Disabilities Council is divided into 8 regional councils corresponding to 8 of the 13 state economic development regions; these sub-state councils participate in the plan development and grant award activities of the state council and prepare the DD portion of HSA plans and Economic Development Regions, but as will be seen, their relationship to the Area Boards and counties is often unclear, duplicative, or non-existent.

2. Service Provision Strategy

As with all 5 states included in this study, Minnesota's efforts to deinstitutionalize the MR population and develop a community-based care system have been guided by the concept of normalization, stated in DPW testimony before the Minnesota House of Representatives as "...a responsive residential environment which is as nearly normal as possible."¹⁰

The state's normalization concept, however, recognizes an ongoing need for institutions for some part of the MR population which is so severely handicapped that movement to community settings would not constitute a substantially more normal or appropriately therapeutic environment than a well designed institutional program.¹¹ Furthermore, the state has emphasized in law, regulation, and evaluation/planning documents the need for a continuum of community-to-institutional care services based on individual diagnosed needs.¹² While the state does not now have in full implementation the diagnostic tools necessary for such individualized services, and the full continuum is not claimed to exist systematically at this time, the service strategy which has evolved is flexible and pragmatic in spirit if not yet fully realized.

Specifically, residential services within the State's spectrum include an experimental parent income subsidy for home care; some independent apartment living programs, board and care homes (for groups of less than 4), CRFs (serving groups of 4 or more)*, and 10 state hospitals (2 of which serve the MR only). All of these are the responsibility of DPW at the state level.

Non-residential services for the MR include the right to public education – first established for the educable mentally retarded in 1957 and subsequently extended to the trainable mentally retarded school-age population. This program, which parallels in all important respects the 1975 U.S. Right to Education of All Handicapped Children Act, is administered at the state level by the Department of Education and locally by public school districts.

* All but 3-4 of state-subsidized community residential facilities (CRFs) are certified as ICF-MRs, although non-Medicaid eligible clients are also served in these facilities and supported by state cost-of-care grants.

For pre-school children who are for some reason not served by the public school system, and for severely disabled MR and/or CP adults, there exists a Day Activity Center (DAC) program to meet basic socialization needs. DAC is a responsibility of DPW's Community Programs Division, and is administered at the local level by free-standing DAC Boards for each facility. Up to two hours a day may be devoted to work activity programming for adults, which is provided through cooperative arrangements with Division of Vocational Rehabilitation within the Department of Education.

Higher functioning adults -- and those who have "succeeded" at the 'DAC level -- are to be provided with work activity and sheltered workshops and, where possible, transition to full-time mainstream employment through cooperative DPW/Division of Vocational Rehabilitation arrangements.

Health services for those who do not require 24-hour nursing care are expected to be provided from conventional community sources; the state also has an extensive early high-risk case-finding network established by the Division of Maternal and Child Health within the Health Department.

County welfare departments are expected to provide supportive social services to families of MR persons and individuals who reside outside their own homes. There is no provision for systematic family training programs within the state's overall service system, however, and this service appears to rest with voluntary organizations as much as with the state or county welfare departments. Such systematic efforts are required by law for those families participating in the experimental income support program but these services have not yet been evaluated. The state hospitals are responsible for all aspects of resident care except that residents are to attend DACs and public schools off-campus, at cost to the resident's home county, whenever feasible.

With the possible exception of a carefully planned parent training program for the majority of those families who choose to keep their retarded member at home, the State of Minnesota has, at least at the conceptual level, provided a fairly comprehensive and differentiated array of services to meet individual needs and maximize the normalization of the MR population within generally accepted state principles of the limits of community-based program effectiveness for the most severely disabled. The state policy, however, regarding the extent of deinstitutionalization has fluctuated over time and was under study at the time of the site visit.

3. System Finance

The state finances its array of services through a variety of mechanisms, but is most notable for its early and extreme reliance on Title XIX ICF/MR funds for the community residential facilities. As of 1977, of all community-based ICF/MRs in the nation, Minnesota accounted for over 80%. The state currently pays 90% of the required Federal match (approximately 50% of total costs), leaving the counties with a relatively light fiscal burden for such care. Non-Medicaid eligible residents in those facilities are supported by state cost-of-care grants. Residential board-and-care facilities serving four or fewer adults are primarily funded through SSI (for which counties pay .50% of the state supplement) or through state appropriated grants-in-aid to cover costs of care for children, whether SSI eligible or not.* State grants-in-aid are used to support the Day Activity Centers, with a 60% state share required by statute, and grants-in-aid are also used to support the CMHC Area Board's planning and individual counseling functions. The counties must match these funds at 50% of costs remaining after fees have been collected.

Special education is funded through state aid to school districts, up to a level of about half of the direct costs of handicapped children's programs and 65% of the costs of contracted services (e.g., a child's participation in a DAC when the regular school system cannot provide the services needed). The remaining costs must be made up by the school districts.

Vocational rehabilitation for adult MR and other disabled persons is supported by the Federal-state VR program. Support for institutions comes from Title XIX (at a 58% federal share), state appropriations, and county of

* Only Ramsey County has made extensive use of "Professional Foster Care" for MR children, using Title XX, County funds, and SSI. These small homes are subject to less restrictive regulations than ICF/MRs, but are paid lower rates.

origin contributions of up to \$60 per case. Parents may be levied a graduated fee for institutional, other residential, and DAC care.

Although multiple funding streams are involved in supporting the residential-health-education-vocational deinstitutionalization and community based service system, the trend in each over the past decade has been to remove incentives for county welfare departments and school districts to institutionalize the retarded (e.g., almost full state-federal financing for ICF/MR residences, as opposed to county support requirements for school and care for institutionalized patients).

This has been a deliberate policy, although developed and articulated unevenly across the various funding programs over time.

4. The Client in the System

A client who has never been institutionalized enters the service system primarily through application to the County Welfare Department (CWD), although a state hospital or CMHC may also in fact be the first point of contact. It is the CWD's responsibility to arrange for initial assessment of the client's needs, arrange for placement in residential and DAC programs as needed, and monitor the client's progress. In arranging for assessment and service planning, some counties work in tandem with Area MH boards and their MR coordinators, particularly if there is a problem in finding an appropriate placement, and with the state institution if a case is particularly problematic.

When the client is a candidate for deinstitutionalization -- as assessed by the institution or parental request -- the institution and the CWD are to work together to develop an individual plan, identify resources, and make formal arrangement for institutional staff back-up support during the client's transition to community living.

How systematically assessments are accomplished, individual plans drawn up and monitored, and working relationships maintained with the institution's or area MR coordinators is open to question because of the absence of an overall management and monitoring system at the state DPW level. The Community Services Bureau of DPW has been actively engaged in developing and disseminating an assessment instrument developed under a Federal HEW grant (The Minnesota Developmental Programming System) which, when in general use and computerized at the county level, should give the state a much more accurate grasp of the appropriateness of initial placements and client movement through the sequence of developmental milestones and programmatic supports contained in each individual plan.

At present, the state really has no systematic mechanism for ensuring that its concept of individually paced client flow through the system is being effectively implemented, and the real burden of assuring that the concepts are adequately implemented rests in practice with the area MR coordinators, state hospitals when appropriate, and parent/provider groups who are generally accepted as watchdogs over the system.¹⁴

B. Social/Political, Legislative and Program History

1. Origins of State Actions

Minnesota's move towards deinstitutionalization and the creation of a community-based care system -- beginning in the 1950s -- is among the earliest in the U.S. This appears to be due in part to the fact that the National Association for Retarded Citizens, the leading national advocacy group for the MR, was formed in the state -- a fact which simply says that many of the constellation of people who were to spearhead the movement on behalf of better lives for the retarded happened to reside in Minnesota. Why this was the case is beyond the scope of this study, but the presence of such leadership cannot help but explain in part the state's early involvement in innovative MR policies.

In addition, Minnesota has had an undisputed reputation for a progressive and nonpartisan approach to social issues dating at least from the 1940s, i.e., a political climate which is conducive to receptivity to new approaches across the broad spectrum of social services. While such broad assertions are hard to document, all legislators and staff interviewed by the study team supported this view; in one interview with the leading majority (Democratic Farmer-Labor) and minority (Republican) members of the State House of Representatives Welfare and Education and Appropriations Committees, the only point of real disagreement between the two concerned the non-means-tested parent subsidy program – not whether such a relatively radical approach to home care of the retarded should be sponsored by the state, but to what extent, with what needs for cost control and evaluation, etc. Such disagreements as have existed over DI policy have tended to be between the State Senate – supporting institutional shrinkage or closure – and the House of Representatives, many of whose members have vested interests in maintaining the institutions as employers in their districts.

At the same time, the political system within the state has not produced executive or legislative leaders whose reputations have been built and focused upon policy toward deinstitutionalization and community care of the MR and other disabled persons; although a succession of governors and legislators have concerned themselves with these issues, the political leadership's response has been gradualist and somewhat reactive to external proposals of organized advocates, special commission reports, developments in the state-of-the-art for care of the MR, and Federal initiatives to which the state has responded more quickly than many others.

In particular, the state executive and legislature has had to deal with the *Welsch v. Likins*¹⁵ right to treatment suit of 1973 in which the plaintiffs argued that state MR institutions must provide more active and appropriate treatment services for their clients. The state has been ordered to appropriate funds to meet court-ordered specifications, and continues to fight this action on grounds that the judiciary cannot order legislation for the expenditure of tax funds.

However, this suit resulted in the closure of one institution and improvements in staff:patient ratios and other service aspects in others, improvements which have continued in response to the state's need to meet Federal requirements for ICF/MR funding.

No one contacted in the state felt able to offer a concise explanation for the development of the state's MR care system beyond the general comment that it "just happened" as needs and means to meet them -- including Federal funding sources and policy initiatives -- became apparent over time, with strong advocacy on the part of MR groups.

2. Nature of the Legislative Base

The first statute to implicitly recognize deinstitutionalization as a policy was the 1953 creation of the Department of Public Welfare, in which the Commissioner was delegated responsibility for state MR and psychiatric institutions and county welfare departments were made responsible for after care. No appropriations were provided for "aftercare" at this time, but the precedent of deinstitutionalization and local responsibility was established.

More specific acknowledgement of the need for community mental health and, to some extent, MR services was expressed with passage of the state's Community Mental Health Services Act in 1957 and the 1957 Special Education Act for Handicapped -- including educable mentally retarded and other DD children in that same year (subsequent amendments required public schools to serve state hospital patients in 1965 and train MR persons in 1971). The next milestone in legislation for MR community services was the establishment of Day Activity Centers (DACs) in 1961; the DACs, which also serve severely disabled cerebral palsied persons, are intended to provide developmental experiences for pre-school children and adult MR persons. In the latter case, the function of the DACs is seen as that of providing socialization experiences and some work activity outside the place of residence for the severely disabled who are seen as unlikely to ever achieve gainful employment.

The next building block in the system was the 1971 enactment by the legislature of a statute authorizing the Commissioner of Public Welfare "to grant licenses for facilities for the mentally retarded and to establish rules and regulations and standards for such facilities and services". DPW responded by developing programmatic standards for Community Residential Services (Rule 34) in 1972. The appropriations bill for 1971 required the Commissioner to "develop comprehensive plans, including recommendations for the future use of state institutions as well as community programs and their relationships to state institutions".* The latter requirement resulted from a Governor's task force on behavioral disabilities report, also issued in 1971, which called for the development of such plans and policies.

In 1973, legislation authorized the Commissioner, DPW, to make grants for the costs of constructing, purchasing, or remodeling small community residential facilities – the first major step toward support of residential resource development. Operating expenses of existing facilities had been borne up to this time by the Aid to the Disabled Title of the Social Security Act (for adults), with state-county funds and the private sector (e.g., United Way) supporting services for children.

Also in 1973, rehabilitation services were extended by law to cover work activity programs to provide basic skill development for severely retarded persons, including the MR. In 1974, specific authority was given to cities, towns, counties, and non-profit corporations to establish community residential facilities for the MR and the legislature appropriated funds for Title XIX ICF-MR community residential facilities to support their development. State zoning processes for such facilities were enacted in 1975, and the small, experimental

* Recent action of the Minnesota legislature relating to the development of community services for the mentally ill, mentally retarded, and chemically dependent. Kevin Kenney, House Legislative Staff, April 26, 1976 (mimeo).

family subsidy program was authorized. This same year, the Commissioner, DPW, was required to present a comprehensive report to the legislature in 1976 detailing a plan to phase down or cease operations at one or more state hospitals. The 1975 MR Protection Act addresses such issues as the rights of the mentally handicapped with respect to commitment, guardianship, and conservatorship and due process to ensure that the MR and other DD persons who are wards of the state are not inappropriately excluded from public schools, and includes provisions for individual evaluation and program planning in appropriate settings.

In 1976, the Minnesota Housing Finance Agency, a quasi-public lending agency with revenue bond authority, was required to make community MR facilities eligible for loans, and the DPW sanctions for violations of its standards for MR facilities was strengthened.

The required report on hospital closures submitted by DPW received no action in the 1976 legislative session, but a Select Committee on Deinstitutionalization was formed by the House of Representatives for information gathering purposes; in 1977, the closing of one state hospital - Hastings --was authorized for implementation in 1978.

The legislative highlights described here reveal that the state has developed its deinstitutionalization and community care system by accretion, rather than through a basic legislative strategy which attempted to authorize most basic services under one authority; at the same time, the authority for the provision of the basic spectrum of services has become fairly complete in law over a span of more than two decades.

3. System Change and Stability Over Time

As the preceding discussion suggests, system development in Minnesota has not been subject to dramatic changes in orientation over time, but has been constantly evolving toward a broader spectrum of community services to meet the needs of the MR, and to a lesser extent, the non-MR cerebral palsied population. This is indicated both by legislation which has added new services in response to identification of new needs and effective advocacy led by the Minnesota Association for Retarded Citizens (MARC). With the formation of the Minnesota Day Activity Center Association (MDACA) in the late 1960s and the Association of Residences for the Retarded in Minnesota (ARRM), established in 1970, an alliance of consumers and providers was formed which has provided added impetus for community-based system development; the effect of this alliance can be seen in the speeding up of legislative activity and state funding for community services since the early 1970s.

The only significant discontinuity in system development has to do with the state's sudden 1974 move to extreme reliance on ICF/MR as a funding mechanism for community residences. ARRM reportedly was among the first entities in the state to see the potential of the Federal ICF/MR program as a funding stream which could significantly expand community residential support, and, working with DPW and HEW's Region V, a six-month pilot project for the state to develop group homes using ICF/MR, with some waivers of proposed Federal regulations (e.g., water temperatures in residential facilities) was undertaken.

The pilot effort seemed feasible to the consumer-provider alliance and DPW as a funding mechanism, and the state legislature was then presented with an appropriation request for community care which was based on Title XIX ICF/MR. No alternatives (e.g., expanded use of SSI for basic board and care)

were seriously considered, and Title XX funds were at or near ceiling for other services by the mid-1970s in any event. The legislature adopted the ICF/MR funding strategy on faith; the pros and cons of utilizing this approach were not presented by the alliance or DPW, and legislative staff is so limited in size that it could not address this strategy independently. Thus, a major funding decision which represents a significant departure from the state's previous, limited financing of community-based care was in many respects a dramatic non-decision — one which, nevertheless, has not changed the state's orientation toward the proper size (15 or less) and service nature of community residences.

Otherwise, regarding administrative change and stability in Minnesota's MR service system over time, the CMH area board/county service delivery mechanism has not essentially changed since it took form, and efforts to integrate this structure into broader geographic and more service inclusive Human Resource Boards have failed, as noted earlier. Somewhat surprisingly, there was no coherent state-level structure for the MR program within DPW until the early 1970s when, again due to pressures from the constituency/provider alliance, DPW created a Community Services Bureau and the legislature mandated the creation of the Mental Retardation Program Office. Previously DPW handled MR system matters through its licensing office, guardianship division, and state institutions division, with little policy or management cohesion or leadership. This was attributed by some consumer and provider groups to the then-incumbent Secretary of DPW's general lack of concern with effective organization in general.

In the brief time since the mid-1970s, state-level staff leadership in MR has been fairly stable, with personnel who are familiar with the state MR system as a result of their previous service in lower levels. CMH Board MR coordinator tenure is reportedly quite stable and lends continuity to

system development at that level, but county welfare department MR specialists in the counties which have such staff – appear to have a high turnover rate. (This is less the case in the metropolitan counties).

Discontinuity in staffing at this basic level does suggest a source of problems in effective planning for and tracking of individual clients, an issue which the state is attempting to address through the introduction of a computerized client data system. On balance, it appears that the stability of the CMH/MR coordinator tenure may be the glue that has held the system together during the 1970s, the period of most rapid system development and expansion.

C. Participant Views of the System

One measure of the status of a state's efforts to serve the MR/DD is the extent of support for or dissatisfaction with these efforts on the part of various participants in the system – state decision makers (elected state officials and their staffs), program administrators at each administrative level, advocacy groups, and providers of services.

In Minnesota, there appears to be, on balance, a cross-cutting agreement on the nature of problems faced by the state, accompanied by a common search for solutions; various aspects of system design and administration are the subject of praise or dissatisfaction by the different sectors involved; in sum, criticism of the system is frequent but lacking in stridency --consistent with the state's system development and political traditions, there is an overriding view that problems are solveable and efforts for improvement will be attempted in good faith by all involved.

1. State Decision Makers

Representatives of the Governor's Planning Office and State Senators, Representatives, and their staffs were in agreement that the state should maintain some balance between continuation of institutions and expansion of community care resources, as opposed to total institutional closure. There was uncertainty and disagreement as to what balance is appropriate and the extent of difficulty which would be encountered in further institutional closures. This group of decision-makers felt that the strongest aspect of the state's system was the mandatory Special Education Act, which in their view has the effect of inhibiting institutionalization and enhancing the quality of life for those who remain in institutions. Major criticisms of the system were focused on three issues:

- The wisdom of overreliance on ICF/MR as a funding source for community residential facilities, both because ICF/MR requirements are seen as driving up costs and imposing unnecessary and inappropriate regulations and procedures on group home operation.
- Over-saturation of community residential facilities in certain areas – a problem hoped to be resolved by a new state zoning law.
- The perceived failure of DPW to be accountable for the system or to serve as an effective advocate for it.

The Department was seen as consistently failing to make a convincing case to the legislature for funds or new initiatives, could not produce data needed for decision-making, and had thus far had to be "taken on faith". DPW

was also seen as imposing inefficient and time-consuming requirements on MR service providers above and beyond requirements generated by ICF/MR. At the same time, these decision-makers did note that DPW lacks sufficient evaluation and monitoring staff and also that many of the state statutes regarding community services to the MR make exercise of state authority difficult vis-à-vis the larger and more independently powerful counties.

On balance, however, DPW was seen as lacking the capacity for dynamic leadership and it was agreed that MARC, ARRM, and other advocacy groups were much more effective in dealing with the legislature over system development issues.

2. System Administrators

State level MR program administrators within DPW concur with the elected officials and their staff that there will be a continuing need for state institutions to serve the extremely disabled population, but also differ in their views as to the probable extent of need and the ease with which reductions in the numbers and size of current institutions can be accomplished.

The administrators also felt that the strongest support for DI and community care over time had been the state's Special Education Act, which not only provided incentives to keep MR persons in the community, but also, because educational services must be provided to those in institutions, largely averted the kind of institutional scandals that other states have experienced. DACs were also cited as a particularly valuable resource for enhancing the lives of the MR, particularly before community residential resource development got underway.

There was very little consensus, even among this small group of state program administrators, with respect to the wisdom of reliance on ICF/MR funding for community care. Some felt that this funding source offered the greatest expansion opportunities for the system and that the most objectionable "medical model" aspects of the regulations had been overcome by creative interpretation embodied in state program licensure, technical assistance to providers in meeting requirements, and so on. Others took the view that ICF/MR regulations, as enforced, were still too medically oriented, inappropriate for normalizing, were driving small, good homes out of the business of care, and slowed resource development because of the complexity of the licensing and certification process. ICF/MR was also seen as creating undue excess costs which would escalate even further to the extent that the state is successful in promoting the development of units with capacity much smaller than 15 clients. All agreed that DPW's special Technical Assistance Program (TAP) had been successful and essential to the creation of resources under ICF/MR.

The administrators, by and large, accepted the criticism that management information systems, and evaluation had not been adequate up to this point, but defended their performance on grounds of insufficient staff, turf problems with the Health Department regarding quality assurance, and the state-of-the-art in measurement. (The latter is under active development in the state.) Finally, the administrators noted that there had been no focal point for community service development for the MR within DPW until the MR Program Services Division was mandated by law in 1974, and no assistant commissioner for Community Programs generally until the same time, so that criticism for poor management might fairly be directed at DPW as a whole, but not at the MR Program or Community Services Bureau.

At the Community Mental Health area/county level, it should be noted that the two area offices visited -- Rochester and Minneapolis -- have quite different area/local structures; in the Rochester area, which includes 3 counties, there is a CMH Area Board, with an MR coordinator who works with the County Welfare Departments according to the overall design of the state system. In this area, there is also a Regional Developmental Disabilities Council associated with the state economic development region which works closely with CMH/MR staff.

In Minneapolis, by contrast, the Hennepin County Welfare Board serves as -the CMH Area Board and MR coordination/planning activities are carried out by staff within the Hennepin County Welfare Department, thus actually performing CMH Board functions. This is a permissible arrangement for the four metropolitan counties in the state. The DD Council in this region does not have a good coordinative relationship with the county MR staff, a source of complaint on both sides.

Despite these differences in structure, the consensus of area MR coordinators, county staff, and DD Council staff was high regarding the strengths and weaknesses of the overall MR system. Those interviewed in both areas faulted the lack of clearly spelled out state policy regarding deinstitutionalization and system development. Within this broad criticism, both groups of area/local participants saw DACs and mandatory public schooling as an important system support and agreed that the ICF/MR rate structure at present stimulated resource development, but were concerned that the ICF/MR "medical model" for service requirements was creating waste by mandating services not needed by higher functioning clients.

Both groups were concerned with the state's overreliance on ICF/MR, anticipating eventual losses in state appropriations (or Federal restraints) which would leave the counties unable to maintain community residential services. In both areas, DPW was seen as providing very weak leadership to lower levels of the MR system, failing to coordinate with other departments with needed resources, and making a poor case to the legislature for the program, in part because of lack of data. DPW's monitoring capability was faulted, and both areas agreed that while some areas and counties had the sophistication to monitor facilities, many did not, so that quality assurance is highly uneven. The state licensure process was seen as inordinately cumbersome without at the same time ensuring that bad providers would be screened out early.

Both areas were able to point to excellent programs within their catchments areas, but felt that these good aspects of MR services had been achieved through county/advocacy group linkages to the legislature and local familiarity with needs and resources. DPW's management capability and role in the development of the system to date was seen as negligible and a serious problem for the majority of other counties and area boards which lacked the sophistication found in Rochester and the Twin Cities. Again, the TAP program mounted by DPW for creation of ICF/MR facilities as seen as highly valuable and necessary to the initial creation of resources under this mechanism.

The two areas were at best mildly optimistic that state leadership would significantly improve in the near future and, while pleased with the accomplishments in service delivery in their own areas, felt that the state MR "system" was not sufficiently systematic in any important respect to protect, equitably distribute, or significantly expand community-based services, as the legislature was beginning to scrutinize costs and performance more closely.

3. Advocacy Groups/Service Providers

For purposes of this discussion, MR/DD and provide group views are treated together because of their basic alliance with each other.

The advocacy and provider groups contacted had few global comments on the clarity of state policy regarding deinstitutionalization and community-based care, other than to note that there was no focal point of policy leadership within state government. Both types of groups accepted as fact that some persons would always require institutionalization, at least under the current state-of-the-art.

As was the opinion of other participants in the system, the advocacy/provider community saw the early mandate for public schooling of the MR and the creation of DACs as beginning the state's real commitment to community care, and both efforts were perceived as generally quite successful.

With respect to criticisms of the Minnesota system, these groups, even more than others cited above, faulted the state's overreliance on ICF/MR funding for community care as being too medically oriented. It was alleged that many excellent small care providers had been driven out of the MR system entirely or had moved to non-MR adult foster care because of inability to deal with ICF/MR requirements. These requirements were not only seen as inappropriate, but as needlessly cumbersome due to duplicative and often conflicting DPW-Health Department licensure and quality assurance procedures. Even so, it was generally agreed that the state's procedures for using the ICF/MR funding stream had been effective in resource development and that rates were adequate to pay for services rendered.

Some groups believed that the very rapid system expansion of the mid-1970s was generating anxiety in the state legislature and were fearful that the movement for DI and community-based care, including necessary expansion of DACs, was losing momentum.

The provider/advocacy groups faulted DPW for its failure to provide effective leadership and maintain credibility with the state legislature; it was further noted that the combinations of weak monitoring systems by DPW and variations in county-level sophistication created a great deal of unevenness in the quality of services from one county to the next.

All groups applauded the Technical Assistance Program (TAP) initiative taken by DPW to assist providers in understanding and meeting ICF/MR requirements and felt strongly that TAP should have been made a permanent feature of the system by DPW.

On balance, the advocacy/provider groups felt that Minnesota's DI-community care system for the MR was better than would be found in most states, although there was a pervasive unease about the possibility of service expansion due to lack of DPW leadership and growing legislative restiveness concerning costs and lack of data.

D. System Achievements

To complete this overview of Minnesota's community care system, it is necessary to address the central question of what has actually been accomplished for the mentally retarded the system is primarily intended to serve.

Ideally, the proportion of those needing a specific service who have actually received it would be a significant indicator of a system's achievements; however, as will be discussed later, such figures have not been agreed upon and cannot, therefore, be used for analysis. Rather, this section will address:

- Trends in the numbers of mentally retarded persons receiving community as opposed to institutional care;
- Trends in severity of retardation among community vs. institutional placements;
- Trends in state expenditures for community vs. institutional services; and
- The proportion of retarded persons served who live in noninstitutional settings and who are gainfully employed.

Qualitative measures of achievement – i.e., how appropriate are the services provided and with what impact on individual quality of life – are of equal importance but are not systematically available in Minnesota. Such evaluations as do exist will be combined with the apparent quality of care in a variety of settings observed by the study team to describe the quality of residential and other community services offered in the state.

1. Quantitative Measures

- Trends in community vs. institutional placement

There has been a clear shift downward in the population of MR persons in state hospitals in Minnesota, from 4,208 clients in residence in 1972 to slightly over 3,000 in 1976.¹⁶ According to a major DPW study by Bock, since initiation of the state's major move to increase the availability of community residential facilities (CRFs) in 1974 under the Title XIX (Medicaid) ICF-MR program, the number of these facilities has grown from 30 to 121 statewide.¹⁷

These facilities together provide a licensed capacity to serve 2,873 MR persons¹⁸. Actual trends in the numbers of MR clients served in CRFs since the 1974 expansion were not available in any accessible form; a major study of Medicaid costs prepared by the State Department of Administration, Office of Management, in 1976¹⁹ reveals the number of Medicaid-eligible MR persons served in CRFs to be almost 2,000. Since the Bock study²⁰ found approximately 400+ unfilled available spaces in toto even though there is an aggregate state waiting list for services, this discrepancy between capacity and apparent number served in community residential programs may be attributed in part to poor matching of geographic location of facilities with need, to management failure to expedite movement of state hospital residents to more independent living levels, and with the remainder accounted for by state "cost-of-care" funded non-Medicaid eligible children.

(NOTE TO REVIEWERS: Please comment/clarify this point.)

The Bock²⁰ and Medicaid²¹ studies do make clear that there has been a regular increase in licensed spaces since 1972, and that the trend in new licensures is toward facilities serving 15 or fewer clients, so that 22 66% of all CRFs now fall into this category²². Supervised apartment programs for the MR have grown more slowly, with only 3 programs of this nature available in the state as of 1976.²³ The slow growth in these programs may be attributed to the fact that most are not now covered by ICF/MR unless part of larger group home organizations.

These data reveal a clear shift in the balance of institutional vs.; community placement for retarded persons since the state began its move to expand community residential care. This shift also represents a near-equal rate of admission to CRFs from state hospitals and natural homes from 1972 up to the first quarter of 1976, at which point proportionally more CRF resident admissions appear to come from the state hospitals.²⁴

There is disagreement among various estimators at this time as to the extent to which the institutionalized population can and should shrink further, and the number of CRF beds likely to be needed by 1980 to provide care for the unknown number of currently unserved among the retarded population.²⁵ These estimates are discussed further under Part III, below.

- Trends in Severity of Retardation Among Community Placements

The Medicaid Cost Containment Report,²⁶ drawing on characteristics of Medicaid-eligible state hospital and CRF clients only, attempted to assess the level of functioning of retarded persons in the different settings based on 1975-76 data.

The definitions used for level of mental functioning are the generally accepted IQ ranges, as follows:

Mildly Retarded: IQ of 52-67 on the Sanford-Benet IQ test

Moderately Retarded: IQ of 36-51

Severely Retarded: IQ of 20-35

Profoundly Retarded: IQ below 20

With this classification scheme, the authors of the Medicaid Cost Containment Report found that state hospital residents were more retarded than those served by CRFs (81% severe/profound as compared to 39% at this IQ level in CRFs). In addition, Activities of Daily Living Scales administered by the State Health Department in 1974-75 as part of its Quality Assurance and Review Program were analyzed in a special report to DPW.²⁷ This report revealed that retarded persons in state hospitals scored highest on this dependency scale (including level of physical disability), while residents of ICF-MR Community Residential Facilities scored lowest.

These same data reveal that state hospital residents are, on the average, somewhat younger (age 31) than CRF residents (average age 37). Bock,²⁸ using the Minnesota Developmental Programming System (MDPS) behavior scales developed and tested through University of Minnesota,²⁹ statistically compared the characteristics of current state hospital residents with the behavioral admission criteria (e.g., level of eating, toileting, skills required) of each of the CRFs. His analyses suggest that, on the average, the admission criteria of CRFs are not substantially different from the average performance of residents of state hospitals on the MDPS scales; Bock statistically projected approximately 420 state hospital residents who would be eligible for CRF placement immediately, with toileting skills of the remaining institutionalized

population representing the greatest discrepancy between "eligible" and "ineligible" populations.

His conclusion is that CRF capacity, rather than differences in the characteristics of clients, may ultimately determine the incidence of movement from institutions to CRFs. The differences in populations served in hospital vs. CRF settings found in the studies cited above are largely attributable to the different measures of functioning used in each.

While the Bock study does not break out the actual placement in different settings by the more standard age, IQ, and physical disability measures reported by the Medicaid study, the overall findings from these studies do consistently suggest that very low-functioning as well as higher functioning retarded persons are being served in the community, even though there is a trend toward serving the less severely disabled, more fully socialized client first. It is somewhat surprising to find that the average age of state hospital residents is somewhat lower than CRF residents, inasmuch as younger persons with no history of institutionalization are typically viewed as being relatively more easy to care for in community settings. However, the Medicaid study suggests that the success of deinstitutionalization over the past few years may be responsible for this deviation from the expected age trend, with only the more severely physically or emotionally handicapped among younger persons being newly admitted to or retained by state hospitals during this period.

In any event, although the data from different sources are somewhat difficult to interpret satisfactorily, it does seem clear that Minnesota is serving a full range of retarded persons in the community as opposed to "creaming" only the highest-functioning for community care. This is consistent

with the normalization concept expressed by the state and by the broader deinstitutionalization movement, even though there remains disagreement among major reports and state MR system participants interviewed as to the extent of the state's success in providing the most normalizing environment possible in an equitable manner across the mentally disabled population.

- Trends in expenditures for community vs. institutional services

Although Minnesota has maintained extensive cost data on institutional vs. community residential facilities and other community MR services (e.g., DAC) over time, it is difficult to report with precision the state's total commitment to each type of service in recent years because of: (1) differing county matching requirements and fiscal obligations across ICF/MR, DAC, state hospital, and other grant-in-aid programs; and (2) a shift to 90% state (as opposed to equal state and county share) of the Federal matching requirement for Medicaid expenditures for ICF-MR community facilities in 1976.

However, for purposes of simplicity, trends in state level appropriations for institutional vs. community care of the MR can be used to reveal overall trends. Figures supplied to the study team by DPW for fiscal years 1973-77 are as follows:

(NOTE TO REVIEWER: Some of the expense categories are unclear to us — particularly Community Based Residential Services MR, Cost-of-Care MR Children. Please elaborate on the purpose, county match required, and Federal funding source if any.)

DEPARTMENT OF PUBLIC WELFARE M.R. PROGRAM COSTS FISCAL YEARS 1973-77 STATE FUNDS ONLY*

Activity Description	1973	1974	1975	1976	1977
A. Support for Community Services					
• MR Program Planning & Evaluation	27,759	35,598	64,674	1,079,002	1,644,542
• Community-Based Residential Services for the MR	40,000	9,000	41,000	159,200	1,456,525
• Community Mental Health Area Grants/MR	671,394	794,109	850,266	1,165,166	1,253,743
• Cost of Care Grants for MR Children	1,330,000	1,550,000	2,313,238	2,860,306	3,268,600
• Supervision Family/Guardianship	3,783	4,385	24,775	47,154	93,040
• Medical Assistance Programs-ICF/MR	0	464,607	1,630,203	2,301,093	6,370,903**
• Grants in Aid for DACs	1,212,840	2,071,889	2,200,021	6,617,811	7,029,480
TOTAL STATE COMMUNITY SERVICE SUPPORT	3,285,776	4,929,588	7,124,177	14,229,732	21,116,833
B. Support for State Hospitals	31,103,140	33,738,450	38,252,700	44,024,955	47,890,170
TOTAL STATE APPROPRIATIONS	34,388,916	38,668,038	45,376,877	58,254,687	69,007,003

* Supplied by Mr. James Hinker, Deputy Commissioner, DPW, August 1977. Table has been reordered to clarify types of expenditures

** State take-over of 90% of Federal match

These figures reveal that, while appropriations for institutions for the MR have accounted for the majority of state funds throughout the period under review, their proportion of total state investment in comparison to funds appropriated for community residential and other major community services has shrunk dramatically from 90% of total state appropriations for the MR in FY 1973 to 69% in FY 1977. Because county DAC matching has typically been closer to 60% than the 40% stated in the DAC law,³⁰ the total expenditure increase for the state in DAC investment is considerably underestimated by these figures; similarly, the rate of investment growth in ICF-MR community residential facility prior to FY 1977 is understated due to the 50% matching funds contributed by counties prior to the state's move to provide 90% of the Federal match.

Overall, these data suggest a dynamic, across-the-board increase in the state's investment in deinstitutionalization and community care resources with a much more static growth trend in state hospital investment. Some of the factors accounting for the continued large share of total MR expenditures by the state hospital system, even in the face of declining enrollments and a public policy supporting increased community-based care, are discussed in Part III, below.

- The proportion of mentally retarded/developmentally disabled persons who live in non-institutional settings and who are gainfully employed

As noted above, the state does not maintain clear data as to the actual number of MR/DD persons served in CRFs or who live at home. Estimates differ by source and methodology employed. Mr. Ardo Wrobel, Director of the DPW Division of Mental Retardation Services, estimates that there are approximately 3,375 MR persons in state hospitals with "about 3,000 more persons in 31 community facilities for the retarded".³¹ He further estimates a waiting list of 600 for CRFs, with one-half from the state hospitals and one-half from the community.

Bock³² examines the proportion of movement to and from CRF settings to provide a more dynamic picture of the extent to which clients served within the state system are in fact being provided with more "normalizing", independent environments. It is important to note Bock's finding that the current status of a substantial number of clients could not be accounted for in his study due to inadequate recordkeeping by the CRFs. General trends he was able to identify reveal, however, that from 1972 through the first quarter of 1976, CRFs admitted approximately equal numbers of clients from state hospitals and natural homes, with a trend in 1976 to increased proportion of admissions from state hospitals. These data are interpreted to mean that greater levels of independence -- whether to large, medium or small CRFs -- have been achieved for many state hospital residents. While movement to a CRF -- especially an ICF-MR of any size -- from the natural home could be construed as movement to a more restrictive setting, Bock and most system participants view this phenomenon as evidence of unknown potential demand appearing as supply of needed alternatives becomes available. This is colloquially termed "the woodwork phenomenon" in Minnesota (i.e., as CRF alternatives appear and become known, MR persons in need of non-institutional residential care will come "out of the woodwork" to fill the new spaces)

Of greater importance, discharges of clients from CRFs of any type to more or less restrictive placement settings from 1972 to 1976 show a constant decrease in discharges to state hospitals, with an increase in discharges to more normalizing settings (natural home, independent living, supervised apartment living) although the total numbers are relatively small (342 discharged to natural homes, 311 to independent living, 125 to supervised apartments from 1972-76).

On balance, discharge trends from CRFs have been preponderantly in the direction of more normal settings, with relatively few discharges to nursing homes and other more restrictive forms of care. Bock³³ speculates that far more discharges to supervised apartment living in particular could have occurred had more such programs been available. The inadequacy of the data system for tracking clients – to be discussed further in Part III – precludes further judgments about the state's record in achieving greater overall independence for MR clients, but the available data suggest that a flow of greater to lesser restrictive settings is being achieved.

With respect to economic independence, as measured by gainful employment for clients served by the system, no statewide data on the employment status of MR/DD persons were available. The Developmental Disabilities Task Force of the Metropolitan Health Board, 34 a component of the Metropolitan Council of the Twin Cities Area, reports that of over 2,000 adult MR/DD persons in the 7 county Metro area, 261 were placed in competitive employment (primarily unskilled and semi-skilled) in 1975-76. All of these placements were from the Twin Cities Metropolitan Area.

The authors of the Report, while acknowledging that employment of the MR/DD will fluctuate with overall unemployment rates, fault both the broader community's attitude toward hiring developmentally disabled persons and the possible failure of the existing DAC/Sheltered Workshop system to socialize and train DD persons to acceptable levels of work habits to make them more attractive to private industry.

In any event, since the preponderance of MR and other DD persons are found in the Twin Cities area of the state, these figures reveal what is surely an overall state-wide problem with respect to providing meaningful employment opportunities for a significant number of adult MR/DD persons who have been served in institutions or the community.

2. Quality of Services

The Medicaid study attempted to provide an overall assessment of the quality of care provided MR persons in state hospital and CRF settings by reviewing the extent to which each fully met Rule 34 DPW Program criteria for ICF-MRs. These criteria apply both to state hospitals and CRFs financed all or in part by Medicaid. Based upon data supplied by DPW, the Medicaid study³⁵ reports that in 1974 state hospitals had a mean of 12.5 Rule 34 deficiencies compared to a mean of 17.1 for CRFs in 1977; state hospitals had an average of 24.8 deficiencies, with CRFs having 35.1. The range of deficiencies cited for CRFs was greater in both years.

The authors speculate that the larger number and range of deficiencies among CRFs may be due to the relative newness of many of these facilities and lack of inter-rater reliability in applying Rule 34 standards and criteria.

On balance, the Medicaid study concludes that, given these caveats, services to the MR in Minnesota are of acceptable if not necessarily exemplary quality, considering the high standards of normalization against which they have been assessed.

As an additional check on quality of services, the Medicaid study group reviewed the Quality Assurance and Review Summary Report³⁶ regarding appropriateness of existing placements as assessed by adaptive behavior/

physical disability ratings. The major findings of this Report revealed that there were 1423 MR residents (primarily elderly and physically ill) of general skilled nursing and intermediate care facilities, for whom this level of care was judged to be overly restrictive and inappropriate for 282; this problem was not seen as one of great magnitude, but did point to a need for better management of placement decisions.

As was done in the remaining four states included in this study, a small, sample of different types of community services for the MR was visited by the study team.

It is important to note that the study team did not perform any systematic assessments of program quality nor was the team technically equipped to do so. Rather, the assessments reported here reflect only the observations, based on brief visits, of persons familiar with a range of services in other states.

MR facilities visited in the Rochester and Minneapolis areas included a state hospital campus serving residents and the community, two work activity/sheltered workshop programs, two group homes serving adults, and a large group home serving children. Although some supervised living apartments were present in the Twin Cities area, the study team was not able to schedule visits to these sites. Descriptions of the sample of facilities are set forth below.

- Rochester Mental Retardation Center

This state hospital, said to be the best in the state hospital system, serves 156 MR persons in residence. The Area Mental Health Center is co-located with the hospital on a pleasant campus which is non-institutional in appearance -- in part because \$600,000 had been spent recently for

renovations to bring part of the facility up to ICF/MR standards. Residents are housed in different small units or wings according to overall level of functioning and age. The hospital maintains a Day Activity Center on campus which provides social adaptation services for pre-school and older residents, while all 59 retarded residents under age 21 go off-campus daily for public schooling. A special education unit is maintained on campus for persons over 21.

In addition, the state center maintains 5-7 respite beds which may be used by community residents for up to 3 weeks as needed. Forty-two MR residents have been placed in the community since the deinstitutionalization movement began in earnest in the mid-70s. The majority of these are high-functioning and the Center works in cooperation with the Area Board and County Welfare Department in evaluation and diagnosis of new MR cases in order to make joint placement recommendations. However, no cases are accepted without formal County Welfare Department referral.

Center administrators and staff report that they are now receiving proportionately greater numbers of very low-functioning or higher-functioning MR persons with behavior problems, as community residential facilities see the state Center's role as preparing such persons for community life. Once the Center staff feel that a client should move to a less restrictive setting, Center staff, parents, and county workers jointly determine the placement.

Fees scaled to income are charged to non Medicaid-eligible parents.

The philosophy of the Center is geared toward preparation for deinstitutionalization, with Minnesota Developmental Programming System behavior goals established for each resident and many realistic activities

(e.g., resident-run canteen, work discipline training, money management, and community orientation) are provided for adults. In addition to serving as a respite and advisory resource to the community, the Center also operates a largely voluntary community-funded camp which is available to all retarded persons in the area for summer recreation. There is a low staff:resident ratio, and it was the opinion of the study team – supported by the area MR coordinator – that this state center is a model for effective institutional support to community-based care of the retarded.

• The Ability Building Center (ABC) – Rochester

The Ability Building Center in Rochester provides some work activity services in cooperation with a Day Activity Center in the area. However, the major roles of ABC are to provide evaluations of work potential and training needs for MR and other developmentally disabled persons under contract to the Department of Vocational Rehabilitation; to provide a part-day work activity and part-day work adjustment/community orientation and adult socialization program; and to provide sheltered workshop training for individuals who have achieved this level of productivity after moving through the lower levels. A staff:client ratio of as low as 1:7 for severely disabled clients is maintained to ensure appropriate monitoring and supervision. Over 300 clients are served by ABC within a given year. While in general appropriate tasks were available to each, a staff member did note that mentally alert DD persons often did not have sufficiently challenging tasks to enhance their further development. Contracts with private industry provide the largest portion (\$600,000) of the ABC's \$900,000 annual budget.

While ABC appeared to meet individual needs in an exemplary fashion, and hopes to move as many clients as possible into competitive employment, the majority of its clients enter at such a low level of functioning and/or have significant behavior problems so that a very small proportion "graduate" from the program into independent employment. Staff also noted that among those clients at the sheltered employment level, reductions in SSI benefits which occur with increased earnings reduced the incentive to enter the competitive market.

- Opportunity Workshops (Twin Cities Area)

Opportunity Workshops, a non-profit organization, is virtually unique in the state in providing both a structured sequence of work experiences for adult (age 18 or over) MR and mentally ill clients and maintaining a residential facility for 60 MR clients. (The latter is an ICF-MR.) Any client referred to the program is first evaluated (at DVR expense) and provided with a four-week work adjustment training period in which basic work discipline is developed through a behavior modification program. Most clients at entry have sufficiently serious behavioral disorders to require this four-week adjustment period regardless of their level of intellectual functioning.

Once this adjustment period is completed, the client is placed in the work level most appropriate to his/her individual needs and capacities; programs include basic skill training, work activity with a socialization component, and sheltered workshop (contract) work which is generally preparatory to competitive employment. Four hundred disabled persons are served in the training facility, of whom 60% are mentally retarded; approximately 100 persons staff the facility. Staff report that, of those persons who reach the sheltered workshop level, 70% are placed in competitive employment (at food, janitorial, warehouse, and a variety of other occupations).

Relatively few among this group are able to achieve totally independent living, but many move on to smaller ICF-MRs or other supervised arrangements. Opportunities Workshops staff noted that even for those who might be able to live independently, their earnings, after SSI benefit reductions, made housing extremely difficult to locate.

It is important to note that, as was the case with the Ability Building Center, these program operators do not assume that all clients can or will be candidates for competitive employment; for many, centers such as these provide a more challenging environment than the essentially socialization-oriented DAC, but must be considered a form of long-term maintenance for individuals who cannot compete successfully in the stresses of the marketplace. At the same time, in both instances low staff:client ratios appeared to assure that clients, regardless of their rate of progress, received individualized attention and work activities appropriate to their level of functioning.

- Sixth Street House (Rochester)

The Sixth Street House, operated by the Olmstead County Association for Retarded Citizens, serves six severely/profoundly retarded men aged 18-39. The attractive house in a suburban setting, open for only 14 months, had required \$15,000 in remodeling costs to meet ICF/MR standards. While staff reported that these costs would eventually be recaptured through rate negotiations, financing the start-up of the home before a provisional rate was assigned by DPW had been difficult and community donations were used for front-end costs.

Of the current residents, 4 of 6 were receiving SSI benefits, while the others had independent income and paid board and care. None of the clients were present at the time of the visit because, consistent with normalization

policy and state regulations, each was engaged in a day activity off the premises — one in a DAC, two in public school, two in a sheltered workshop, and one was competitively employed part-time and participated in sheltered work part-time

While the home had started with untrained houseparents, the staffing pattern had shifted to the use of more professionals, contributing to per diem costs of \$34.24 in 1977. The Sixth Street House manager reported that DPW's Technical Assistance Program (TAP) had been invaluable in getting the home started, but that program monitoring was weak — "the parents are the real monitors".

- Hiawatha Children's Home (Rochester)

Although Minnesota state policy increasingly promotes the development of ICF/MRs housing 15 or fewer residents, the Hiawatha (non-profit) Children's Home was issued a county revenue bond to construct a 40-bed facility in order to meet the urgent need for community alternatives to state institutional care which existed in the area in the early 1970s. Hiawatha opened in July, 1976, and served 29 severely/profoundly retarded children under age 21 as of July, 1977. Of the children served, 25 were in public school and 4 pre-school children attended a local DAC; four respite care beds are maintained for use by MR children residing with their parents. The staff:child ratio at the time of the site visit was 3:1, with a \$40.23 per diem rate assigned by DPW.

The one-floor facility is attractive and located on a pleasant residential street. Because of its size, it was able to meet ICF/MR requirements more easily than subsequent smaller homes. Hiawatha has reportedly

enjoyed a high degree of community support and a good relationship with county social workers, DACs, and the school system. Clients are drawn from 10 surrounding counties and a few are from out-of-state. Staff reported that the MDPS had been very helpful in diagnosing and setting individual goals for the children, and the overall ambience of the home, despite its size, was not institutional in the invidious sense of the term.

- Outreach, Inc. (Twin Cities)

Outreach, Inc., is a non-profit organization operating 5 group homes. Previously, the organization had owned a 100-bed facility but had sold it to a for-profit entity because of problems in securing an adequate rate.

The home visited was located in a pleasant neighborhood in northeast Minneapolis and served 6 adults – 4 men and 2 women, aged 23-40, all of whom were in the severe to moderate IQ range but functional at a moderate level. All of the current residents in the home visited work at Opportunity Workshops and are seen as having high potential for long-term independent living; the expected stay for all clients accepted by Outreach, Inc., is 5-7 years and in the home visited -- open for only 3 years -- the first resident was scheduled to move into an apartment training program within the month. The Outreach, Inc. coordinator and houseparent were extremely outspoken on the subject of client rights, and felt very strongly that sex-segregation of adults was not consistent with the normalization principle. In the same vein, both staff objected strenuously to many ICF/MR requirements as interpreted by various state agencies (e.g., no objects other than furnishings permitted on floors) as being unhome-like, time-consuming, and

driving up costs unnecessarily. (This home had a per diem of \$26.50, pegged to the level of functioning of clients, but still felt a cost squeeze due to bookkeeping requirements and other administrative costs.)

As with the small group home in Rochester, Outreach, Inc., staff noted problems in start-up financing for small operators even though these costs would eventually be recouped through rate setting; the whole overlapping licensure process in the state was a source of considerable complaint, but the TAP effort mounted by DPW was seen as essential to program start-up under ICF/MR. The study team was present when residents returned to the home at the end of their work day and it seemed clear that this home was providing an excellent developmental environment.

This completes our overview of the State of Minnesota's deinstitutionalization and community-based care effort. In Part III the State's approach to each key system element is reviewed.

III. MINNESOTA'S APPROACH TO THE KEY SYSTEM ELEMENTS

This part examines Minnesota's approach to each of the eight key system elements identified in Chapter One and the extent to which the effectiveness criteria for each element are met.

A. System Organization

1. Clarity of MR System Objectives

At the broadest level, as reflected in the 1971 statute expanding the licensure authority of DPW, and particularly in Rule 34 pursuant to this law, the objective of normalization for the MR is clearly set forth, i.e., "...The purpose of the licensing law and these regulations is to establish and protect the human right of mentally retarded persons to a normal living situation, through the development and enforcement of minimum requirements for the operation of residential facilities and services. Moreover, these regulations serve an educational purpose in providing guidelines for quality service."³⁷

The normalization concept, as expressed in the 1975 Comprehensive State Plan for Mentally Retarded and Developmentally Disabled in Minnesota,³⁸ includes a developmental service model and individualization of services to the MR/DD. It gives priority to services to MR/DD persons which will enable them to live in their own homes, followed by individually appropriate community residential facilities for those who cannot remain at home, and placement in state institutions when suitable community programs are not available.

The 1975 Community Alternatives and Institutional Reform (CAIR) Report,³⁹ which has been adopted by DPW as a guide to system development, further supports and refines this normalization objective. It specifies a

continuum of residential programs appropriate for clients with different characteristics and levels of functioning and explicitly recognizes that institutional care may always be most appropriate for some MR/DD persons.

However, there are two aspects of the state's objectives which are somewhat confusing. First, the DPW Comprehensive Plan and the CAIR report upon which it relies to a large extent, refer to normalization for the MR and DD. There is no state legislative or regulatory authority for institutional or community residential services for the non-retarded developmentally disabled. The latter groups are only included in the Right to Education of the Handicapped law, and cerebral palsied persons are eligible for DAC services. At the time of the site visit, expansion of community-based residential facilities to encompass other DD persons was not being actively debated as a policy objective.

The other aspect of the state's objective with respect to deinstitutionalization and a community-based care system which is unclear in law and DPW policy concerns the relative balance between further deinstitutionalization and expansion of the CRF system. The 1976 Medicaid Cost Control Report,⁴⁰ prepared at the request of the Governor, addresses the issue primarily from a cost and quality perspective; alternatives analyzed include deinstitutionalization (DI) of all retarded persons, DI of all borderline/mildly retarded MRs, DI of all borderline/mildly and moderately retarded residents, and DI of all but the profoundly retarded resident population. The authors of this complex analysis recommended a policy of greatly increased deinstitutionalization, with minimization of length of stay and intensity of care when institutionalization is unavoidable. In addition, they recommended increased attention to alternatives to residential placements per se, i.e., supervised apartments and family subsidies, neither of which have been clear DPW objectives, although MR Program Office officials interviewed expressed an intent to pursue expansion of supervised apartments in the future. The Report emphasized the need for firm policy decisions as soon as possible so that adequate planning for hospital closure and expansion of community residential alternatives could proceed.

At the time of the site visit, the Bureau of Residential Services was considering an options paper about the appropriate role of the state hospitals; this paper, which had received extensive review and comment from the state hospital directors, suggests that the hospitals would necessarily have to provide regular residential services for the severely/profoundly and multiply handicapped MR population, but should expand their role to include respite care, short-term training and treatment, consultation to community programs, staff training for residential facilities, research, etc.

The Medicaid Report and Hospital Options paper reach quite different conclusions regarding the degree of future deinstitutionalization to be sought, in no small part because of differing assumptions and data regarding the potential for successful and cost-effective community care for the most disabled. This lack of clarity of the state's objectives regarding deinstitutionalization and community care threatens the effectiveness of the state's approach to system organization if these issues are not resolved soon.

2. Authority and Responsibility for Overall Achievement of Objectives

Even though there is lack of clarity in the balance between the state's DI/community based care objectives, the 1971 licensing statute in particular appears to grant the Commissioner, DPW, authority to determine and implement such objectives, i.e., "...The commissioner of public welfare may (emphasis added) determine the need, location, and program of public and private residential and day care facilities and services for mentally retarded children and adults."⁴¹

This authority applies to CRFs, DACs,, and state hospitals alike. A state MR advisory board is created to assist the Commissioner, DPW, in exercising this authority.

Responsibility for the MR system within DPW has been delegated to the Bureau of Community Services and the Bureau of Residential Services (state hospitals). As expressed in the 1975 Comprehensive State Plan,⁴² it is DPW's philosophy that its role in community care, guided by the normalization objectives, should essentially be confined to broad-based standard-setting, coordination, funding, monitoring, and evaluation functions; management and operational responsibilities should be delegated to the local level.

This philosophy is consistent with the actual constraints on DPW and its constituent units in exercising its legal authority for achieving overall system objectives.

First, with the exception of the state hospitals, Minnesota's community residential service system is a purchase-of-service rather than state-operated one, so that the initiative to offer CRF services ultimately rests with potential providers.

Second, the provision and development of services has been delegated to county welfare departments and CMH Area Boards respectively. Because counties must provide varying degrees of matching funds for CRFs and DACs, and ICF-MR support is not presently available for supervised apartments, the counties exercise considerable discretion as to the amount and type of resources they will support. In addition, CMH Area Boards have responsibility for submitting plans (with county concurrence) for services to be offered. Even so, as of the 1977 site visit, the state-level Mental Retardation Program Services Division was not exercising its inherent authority to deny or significantly modify area objectives and resource plans. Rather, area plans were compiled at the state level with little modification, primarily for

appropriations request purposes. Given the tradition and philosophy of county autonomy in decision-making, it is not clear how successful DPW would be in challenging county/area decisions regarding specific objectives and services to be delivered. DPW can exercise some control by denial of program licensure to facilities, but this also places the state in a reactive rather than positive stance toward meeting objectives.

Finally, the authority of the state to achieve specific community residential facilities objectives (i.e., distribution, size, etc.) is potentially constrained by the provisions of P.L. 93-641, the National Health Planning and Resources Development Act of 1974. Since the state relies on privately-operated ICF-MR level of care for CRFs, these facilities are subject to review and approval for need by state and area health planning agencies. While this does not appear to have been an actual constraint in Minnesota to date, it does limit the authority of DPW regarding the shape of the community residential care system. (In practice, counties and area boards visited reported having used the health planning review mechanism to obtain disapproval of potential providers which they deemed inappropriate by submitting negative recommendations to the Health Systems Agencies.)

With respect to authority to achieve deinstitutionalization objectives, the Bureau of Residential Services, DPW, does appear to have legal authority to bring about reductions or closures of state hospitals. This authority is, of course, constrained by the political implications of such actions as perceived by the state legislature. However, the split in responsibility for community and institutional services within DPW may pose a greater barrier to clear DI objectives. Interviews with officials of both units suggested a lack of systematic coordination between the two, which may be hindering the development of a coherent DI/community care system.

It may be concluded that DPW has adequate legal authority to set DI and community service objectives – an authority which has not been fully utilized to date – but its authority to ensure that such objectives are achieved is very much limited by: (1) DPW's own support of traditional and statutory local control of service investment decisions, (2) the political realities involved in setting and implementing DI objectives which would significantly change the state hospital system, and (3) lack of systematic coordination between the Bureau of Community and Residential Services.

These apparent weaknesses in state-level authority and responsibility in Minnesota to set and enforce system objectives are reported to have led to inequities in access to appropriate community-based services across the state and a confused DI policy. At the same time, local officials may be in a much better position to determine and implement specific objectives for community services in their own areas than is DPW because the state agency has generally failed to exercise the authority it has available to provide effective support to local decision-makers. As will be reported below, however, DPW was actively engaged in building its own leadership capacity at the time of the site visit. If these efforts are successful, DPW should be able to overcome the constraints on its own broad authority and responsibility to achieve system objectives within the framework of local autonomy.

3. Assignment of Responsibility for Key System Elements

The extent to which Minnesota has assigned responsibility at the state and local level for the performance of each key system element necessary to achieve system objectives as defined in this study is described in the following sections.

a. Service Coordination

The 1975 Minnesota Mental Retardation Protection Act mandates the Commissioner, DPW, to assure that mentally retarded citizens who are legally subject to guardianship or conservatorship of the state "...receive the full range of needed social, financial, residential, and habilitative services to which they are lawfully entitled."

These individual service coordination responsibilities -- which are also extended to MR individuals not under state supervision -- may be delegated to CWDs.

According to the 1975 Comprehensive State Plan, the Mental Retardation Program Office is the responsible unit within DPW at the state level for coordination of other agency services needed by the MR/DD (sic) population in Minnesota.¹⁴

The responsibility for ensuring that program resources other than those specifically directed at the MR (i.e., CRFs, DACs) are made available to support the MR program has in turn been delegated to the CMH Area Boards under DPW Rule 185.⁴⁴

Under this same rule, County Welfare Departments are responsible for case management, which requires working with families and with DACs, CRFs, and state hospitals, as appropriate, in determining the best placement for the individual MR person. The agency within the CWD responsible for the placement determination is also responsible for developing, with the family and service provider, an individual service plan which draws upon all public program resources needed to implement the individual's plan.

5. Monitoring and Evaluation

According to DPW Rule 34 (the regulations for residential program licensure), DPW is responsible for monitoring licensed residential facilities. In addition, however, the Health Department is responsible for monitoring for compliance with Federal ICF-MR and other supervised living facility requirements, the state Fire Marshal is responsible for monitoring compliance with the state's Life Safety Code, and the state building code division of the Department of Administration monitors facility compliance with the state building code.

Monitoring of facilities covered by DPW Rule 34 is not officially delegated to the local level, but is performed by state Community Programs Division staff; the same is true of monitoring by the Fire Marshal and State Building Code Division. Eleven regional quality assurance teams from the Health Department monitor compliance with those regulations for which the Health Department is responsible. County Welfare Departments/social service agencies and facility staff are responsible for monitoring individual program plan compliance and evaluating progress, and the Boards of Directors of DACs --which typically include representatives of county welfare departments -- are mandated by the DAC law, as amended in 1975, to periodically review and evaluate the services provided by the DAC.

Responsibility for evaluation of the state's MR system in meeting overall goals and objectives or efficiency in utilization of resources is not clearly assigned to any level by law or regulation.

Needs Assessment

The 1975 Comprehensive State Plan assigns overall needs assessment responsibility to the Mental Retardation Program Office, while the CMH Area Boards are assigned this responsibility at the local level under DPW Rule 185. The State DD Council is administratively assigned this function – as are the 8 area DD Councils – with respect to the broader DD population.

This same rule makes County Welfare Departments/local social service units, with the aid of interdisciplinary teams, responsible for assessment of individual needs. Special education needs of individual children are to be assessed by staff of local school districts, subject to stringent procedural regulations mandated by 1976 amendments to the state Education of the Handicapped Act.

Individual needs assessment for Vocational Rehabilitation for the MR is the responsibility of the state Division of Vocational Rehabilitation, which may contract this function to the public schools or to DACs and private work activity/sheltered workshop programs.

Resource Inventory

The 1975 Comprehensive State Plan assigns overall resource inventory to the MR Program Office, and Rule 185 assigns this role to CMH Area Boards. As with needs assessment, state and regional DD Councils are also responsible for resource inventory for the larger DD population.

e. Planning and Priority Setting

The Division of Mental Retardation (MR Program Office) within DPW is responsible for broad planning and priority setting for the MR at the state level, apparently including both institutional and community-based services. The Developmental Disabilities Council within the State Planning Office is responsible for planning for the DD population in general. CMH Area Boards perform the priority setting function for the MR locally. Regional DD Councils develop plans and priorities for the DD within their region. These councils also generally write the community residential facilities portion of health systems area plans.

f. Coordinated Funding

This key element is legally the responsibility of the Commissioner, DPW. The Division of Community Programs appears to have lead responsibility for coordination of state and Federal funds administered by DPW and by other Departments.

At the local level, Rule 185 leaves unclear the formal responsibility for coordination of funding, and in fact does not actually mention performance of this key element although some such responsibilities might be implied for both the CMH Boards and CWD/social service agencies.

g. Resource Development

This key element is also the legal responsibility of the Commissioner, DPW. The Division of Mental Retardation is delegated responsibility for maintaining a system of management, fiscal, and policy support to the CMH Boards in developing community resources, but operational responsibility clearly rests with the Area Boards.

While the actual implementation of the key system elements will be addressed in detail later in this part, it may be concluded at this point that Minnesota has failed to address and assign responsibility for some aspects of these elements -- notably system effectiveness and efficiency evaluations and funding coordination below the state level; the other key elements within the MR service system appear to have been provided for through law and regulation with reasonably clear assignments of responsibility, although DPW Rule 185 was promulgated only in 1977 after several years' confusion regarding the definition of and responsibility for many "system elements" at the area/ local level.

4. Clarity of Lines of Authority

With the exception of those key elements which are not fully addressed by law, regulation, or administrative decision, the lines of authority -- which units report to others and for what purposes -- are reasonably clear in Minnesota, as indicated in the above discussion. The central reporting relationship for program operations is between the CWDs and the state Division of Community Programs/Bureau of Community Services; for planning and resource development, the CMH Area Boards report to DMR. However, three areas in particular appear especially problematic: first, the state and area DD councils have no line authority over any other units, and are not integrated with the MR structure. As a result, DD planning efforts are related to the MR system only in areas where a coordination commitment exists between regional councils and area boards. This represents a duplication and waste of effort for which there were no plans to create remedies at the time of the site visit. Second, neither DPW Rule 185 nor any other rule or law makes clear in practice who is responsible for clients who move from one county/area to another, and it is alleged that many clients

are "lost" in the system as a result. Finally, counties have responsibility for ensuring that appropriate resources are used to meet individual service plans, and Area Boards are responsible for developing such resources if they are not available; however, licensing authority for CFRs rests with the state, which may or may not abide by Area recommendations with respect to need and appropriateness. Confusion of authority and responsibility over this issue appeared to the study team to be one of the weakest aspects of system organization in Minnesota. This aspect of the state's approach to this key element will become a more serious obstacle to systematic provision of services to the MR in the future as state policy-makers become more concerned with total costs and the provision of a full continuum of care resources.

B. Service Coordination

In this section the extent to which Minnesota's efforts at service coordination meet study criteria for effectiveness will be examined.

1. State MR agency identification of the range of resources which should be coordinated at the point of delivery and communication of this information to responsible local unit.

There has been considerable concern over time on the part of the state's Governors and legislature regarding human services coordination in general; to address this concern, the Human Services Act of 1975 was passed to provide for Regional Human Services Boards which would have enhanced statewide capacity to identify and coordinate resources needed by the MR as well as others. Since, as noted in Part I, counties resisted the Human Service Board concept, an office of Human Services within the State Department of Administration was created by the legislature in 1975 with a mandate to

evaluate Minnesota's Human Service delivery system and to make reorganization recommendations to the 1977 legislature. This office recommended a state level reorganization of services into a Department of Economic Security and a Department of Health and Social Services, with local level "one-stop" service centers for each Department. These recommendations were under debate and awaiting legislative action at the time of the site visit, and prospects for approval of such a massive reorganization were unclear.

This level of state elected official concern with service coordination in general was matched to some degree regarding the MR within the DPW Bureau of Community Services/Division of Mental Retardation staff. Efforts were underway to create a computerized Management Information System through which services needed by and provided for MR clients could be identified. It was hoped that such a system would make clear where better service coordination was needed and would provide the data base necessary for identifying service gaps which should be filled by other existing programs or new resources.

Up to this time, however, there does not appear to have been a systematic effort on the part of DMR or the Division of Community Programs to identify resources controlled by other Departments or agencies at the state or sub-state level which should be tapped for services to the MR. DMR and DCP have not formally communicated information of this kind to area Boards or CWDs. The Division of Social Services within the Bureau of Community Services does include in its planning guidance to CWDs for their annual social service plans a list of resources to be tapped to support services to 45 the various populations to be served,⁴³ but this list is not very explicit or inclusive.

The state DD Council Plan does identify agencies and the state/ Federal resources they administer in some detail, although how well this information is disseminated to CMH areas – particularly those which do not work closely with regional DD councils – could not be determined.

The DMR performance with respect to this study criteria must, however, be seen in the context of the state's statutes, regulations, and system organization. First, many resources which would otherwise have to be coordinated from different programs run by different levels of government are built into the variety of state laws and regulations which comprise the DI/MR system. For example, transportation from the place of residence to a DAC is funded 100% under the DAC act, and DPW Rule 34 requires CRFs to ensure that residents attend DACs if this is part of their Individual Program Plans (IPPs). School Boards are required to pay for transportation to DACs for any school age MR children for whom DACs are used to supplement or replace regular public education. Similarly, resources for work activity and sheltered workshop programs are provided specifically for the mentally retarded under 1973 state law. The DVR thus is mandated to serve the MR, and transportation costs for clients to attend rehabilitation centers are also provided for under the statute.

Thus, many transportation needs are met without the need for identification of supplemental resources for coordination.

Funds for CRF construction are made available by the Minnesota Housing Finance Agency under 1976 law. Basic support for CRFs, including remodeling of facilities to meet requirements and the developmental activities they are required to provide within the facility, is covered by ICF/MR appropriations and DPW Rule 52 (ICF/MR rates). The state grant-in-aid for costs of care supports CFR services for non-Medicaid eligible clients.

The DAC and state

vocational rehabilitation programs provide for training and stimulation outside the clients' residence. Again, resources which would otherwise require special identification efforts are built into the system. This is not to say that DMR does not have work to do with respect to resource identification and communication to CMH Boards CWDs, and CRF providers; DMR staff acknowledge that they have been slow in exploring other sources of support (e.g., Section 8 of the Housing and Community Development Act) for supervised apartment and independent living, aspects of the state's desired continuum of care which are barely developed at this time. Staff felt that their recent preoccupation with the development of ICF/MRs, combined with DMR staff shortages, had precluded more aggressive exploration of resources for this or other purposes.

In fact, the lack of greater state level effort at resource identification and communication of such information to sub-state units does not appear to have had adverse effects in the two CMH Areas visited; both were very much alert to alternative funding possibilities and, as will be seen, one had successfully acted on several. At the same time, the study team was cautioned by several system participants interviewed that the less sophisticated, more rural CMH areas and CWDs were less likely to be able to identify and obtain additional resources which should be coordinated at the point of delivery.

On balance, it may be concluded that the necessity for state action regarding this study criteria for the service coordination key element is reduced by the built-in resource availability and coordination provided through state laws and regulations; at the same time, DMR has not been able to effectively and systematically identify resources which are needed to further develop the continuum of care or to ensure that all CMH areas/CWDs have the information they should have about other resources to bring about optimal coordination of services for clients.

2. Development of agreements between state MR agency and other state agencies which control resources.

Consistent with the discussion above, DPW/DMR has not had to make great effort to negotiate resource coordination agreements with many other Departments or agencies because of the nature of state law. The only written agreement in existence affecting the MR appears to be between the Social Services Division of DPW and the DVR/Department of Education concerning the terms of DPW purchase of DVR Work Activity and Sheltered Workshop Services for MR persons who are income eligible for Title XX Social Services⁴⁶. Otherwise, DMR staff report that they have close linkages with the Division of Special Education/Department of Education and DVR but no formal agreements regarding service coordination.

In any event, the major resource coordination gap -- housing for supervised apartments and independent living -- would require agreements between sub-state housing authorities and CMH Boards/CWDs because Federal housing law gives authority over these resources to such sub-state units.

3. Local MR/DP agency resource identification and development of coordination agreements.

The two CMH Areas visited addressed this study criteria in very different ways due to differences in their organizational structures and procedures.

The Zumbro Valley Community Mental Health Board MR staff (based in Rochester) has an advisory committee which includes representatives of the area's CWDs, the local MARCs, and service providers (DAC, CRFs, etc.) who,

collectively, are able to inform the MR coordinator of resources which are potentially available and needed for the area's MR/DD service system. Area MR staff also sit on the Boards of individual providers (DACs, CRFs, etc.) and share resource information with them. Beyond this, in Olmstead County (Rochester) there is an unusual structure, the Human Services Management Committee, which is a good point of access for information and informal coordination agreements for the area MR staff. Finally, unlike many other areas in the state, the CMH area MR coordinator works closely with the Regional DD Council so that there is continual flow of information regarding resource opportunities within the entire Economic Development Region.

This area MR coordinator, who is personally intensely concerned with achieving greater resource coordination, has not found it necessary to attempt to develop formal resource coordination agreements across agencies for most aspects of services due to this interlocking structure. However, he and his advisory committee reorganized the need for resources for semi-independent and independent living facilities, and were exploring HUD (Section 8, rent supplements) coordination potential within the area at the time of the site visit. In addition, the MR coordinator, together with the chief of research for the Bureau of Community Services and DMR, was attempting to obtain Federal DD funding for a pilot Management Information System designed to facilitate, among other things, resource coordination at the point of delivery. The area staff had facilitated the development of contracts with CETA for job training by DACs, but the MR coordinator felt that by and large this was not an effective effort because trainee turnover creates discontinuities in staff which adversely affect MR clients. A few positions for CETA trainees had been retained by some DACs and this was successful. The MR coordinator observed that local CETA programs are reluctant to accept MR persons as trainees because most are eligible for SSI income and/or DVR training;

therefore, the MR are not a priority for direct training by CETA. One additional formal inter-agency coordination effort by the CMH area MR staff was a transportation coordination program funded by the Federal Departments of Transportation and Office of Developmental Disabilities, with county matching and continuation support. This coordination effort fills gaps in the transportation services mandated by state laws and provides for a more streamlined, unified approach to transportation for the MR/DD in the area.

In Hennepin County (Minneapolis), CMH area functions are performed directly by the Mental Health/MR/CD division of the county Welfare Department, which does not utilize an external advisory committee and does not work closely with the Regional DD Council. Hennepin County CWD/MR staff is included in the Metro Area Council which encompasses the twin cities and adjacent counties, but Hennepin essentially "goes it alone" with respect to all of the key elements.

Hennepin County staff, like the Rochester-based CMH area staff, were very much concerned with service coordination per se, but were somewhat less active in attempting to identify and develop any type of agreements for service coordination with sub-state agencies having resources which could be utilized for the MR program. Rather, apart from ongoing coordination with school boards and DVR, the MR staff focused on getting the CWD to support --directly or through state community services grants to the county department --the development of supervised apartment programs, recreational services for the MR and cross-disability programs (e.g., mentally ill MR persons). Resource identification and coordination agreements in this county thus essentially took the form of internal negotiations within the CWD to support inclusion of the MR Division's resource requests in the CWD budget.

While each area's approach to this study criteria seemed to be adequate at present for achieving coordination of resources to meet area MR program needs, the study team believes that Hennepin County would benefit from a more aggressive effort to identify and coordinate with agency resources other than those provided specifically for the MR under state law and regulations. Limitations of staff time are a consideration which must, in all fairness, be taken into account.

4. Provision for ongoing coordination of services for individuals through the case management function.

DPW Rule 185 attempts to make clear that ultimate responsibility for ongoing case management rests with a local social service agency within CWDs, and also mandates that these agencies ensure that there is coordination of services to fulfill Individual Service Plans (ISPs).

The actual task of obtaining services needed for an individual in a CRF served under DPW Rule 34 rests with the facility; the facility is responsible for maintaining records on health status and developmental progress and for coordinating this information with that of schools, DACs and other providers serving the individual.

However, at the time of the site visit, there was still considerable dissatisfaction at all levels of the MR system with the actual performance of the case management/service coordination function, and some doubt that Rule 185 would lead to much improvement. Indeed, in a grant proposal for a Management Information System pilot project submitted to the Developmental Disabilities Council by the Zumbro Valley MR Coordinator and the chief of Research, DMR, it is bluntly asserted that there is an "irregular and changing set of points at which one accesses the service system and a serve lack of any authoritative case management function. . . "case planning", where it exists, tends to support the service status-quo, disregarding the concept of development rather than subject the

client to possible loss within the system. . . [and] effective "case management" typically does not exist." 47

Perhaps the best documentation of the latter assertion is found in the February, 1977 DPW study, An Analysis of Minnesota's Effort to Reintegrate its Mentally Retarded Citizens into the Community in which the author sought information on client discharges from all CRFs in the state and found that "a substantial number of clients could not be accounted for in this study. It is not known if these clients were "lost" in the system or if their placements were appropriate to their needs." 48

State hospital staff in Rochester noted that parents of many clients came to them first for evaluation to avoid the 'welfare' stigma. The hospital social work staff would then contact the appropriate CWD unit for a joint case work-up and if the client was placed in the hospital, the hospital sometimes managed the outplacement decision when appropriate; in other instances, the county CWD would participate, as required by Rule 185. Hospital staff attempted to get CWDs to report follow-up data on discharged clients with mixed results, with understaffed counties being least responsive. This particular hospital maintains relations with CRFs and examines new facilities for their adequacy for placement for hospital clients.

The area MR coordinator reported that clients also entered the system through the area mental health center as well as through the state hospital and the CWD, and while he tried to ensure that CWDs took responsibility for each case, there was no assurance that counties could maintain complete and current records on client progress or whereabouts, particularly when a client moved from one county to another. The absence of a statewide management information system was blamed for these flaws in case management and service coordination.

This same MR coordinator faulted counties for the case management of work and training for the MR, stating that these services frequently failed to provide for stages of individual development. As noted in Part I some vocational service providers agreed that this was a problem which they had been unable to resolve with existing resources.

County staff in both sites visited were dissatisfied with the absence of state leadership in the past in providing implementation tools – in the form of adequate measures for case planning and systems for ongoing management – but both were in the process of examining the new MDPS system and adapting it for case management/individual service coordination purposes.

The CRF providers visited did maintain individual plans and records and reported good relationships with DACs, schools, and workshops serving their clients.

To summarize, Minnesota has experienced some problems in ensuring coordination of services for clients through the case management function because the state has lacked adequate management systems to ensure that counties perform case management uniformly well.

The absence of such management systems makes it impossible to document the extent to which available resources are or are not coordinated on behalf of clients, but the consensus of those interviewed at each level within the system is that performance of the case management/coordination function for individuals, is uneven across the state.

However, there was considerable evidence of efforts at both the state and county level to remedy this situation at the time of the site visits.

C. Monitoring and Evaluation

Minnesota's approach to performance of this key element is assessed in this section according to the four study criteria.

1. Clear and Measurable Performance Expectations for Responsible Units Within the System.

The major statement of performance expectations at the state level pertains to the role of DMR as set forth in the 1975 Comprehensive State Plan.⁴⁹ This document, which elaborates on the statute establishing DMR, simply states that the office "is to develop procedures and techniques that enable it to. . ." perform needs assessments, define and evaluate the current delivery system, etc. What is clearly measurable is whether or not techniques and procedures have in fact been developed; how their adequacy would be determined is not spelled out.

Moving to the sub-state system level, DPW Rule 185 clarifies area/county provider responsibilities in general, but leaves unclear in many respects how adequacy of performance would be measured. In reviewing this new Rule, Hennepin County MR staff specifically noted several problems of measurability,⁵⁰ e.g., certain information is to be used in developing the individual service plan "when appropriate", but there are no criteria for appropriateness; evaluation of client progress is required, but there are no specified time-frames; area boards are to "ensure opportunity for involvement" of various agencies in planning and coordination of services, but the mechanisms which would satisfy the requirement to ensure involvement are not stated; and so on. Advocacy groups and others interviewed agreed that DPW Rule 185's biggest failing was with respect to clarity of how it should be implemented, i.e., how performance of specified roles could be determined adequate. Rule 185 does suggest -- though does not mandate -- that CWD/social

service agencies use the new MDPS for client behavioral assessment in developing individual service plans. Other instruments of "comparable reliability and validity" are also acceptable.

Expectations are most clear and measurable at the direct service provider level. The state has used a series of licensure "rules" which have the force of law, to set forth detailed program and administrative requirements for CRFs (DPW Rule 34), physical safety for all residential care of the handicapped (Rule 80) and programming for DACs (Rule 38). In the latter case state staff acknowledged that criteria for intake and duration of service needed refinement. In addition, the Health Department has issued regulations for nursing homes, board and care homes, and all "supervised living facilities", and certifies compliance with ICF/ MR and other Federal health regulations applicable to health-related residential care. DVR has regulations for work activity and sheltered workshops serving the MR. At the time of the site visit, regulations for supervised apartment programs were being developed to complete the spectrum of regulation of CRFs. The existing CRF regulations are certainly measurable with respect to most areas covered; CRF providers found ICF/MR requirements overly explicit and often inappropriate in content for a "normal" living environment. This issue is discussed further under Resource Development.

In the study team's judgment, the clarity and measurability of performance expectation for units within the Minnesota system meets the study criteria best at the provider level, declines with respect to CWD and area performance, and is too vague to effectively provide for needed accountability to the Governor or legislature at the state level.

Special attention should be called to the absence of any clear directives to area boards to develop the full continuum of residential care resources as set forth in the CAIR Report⁵¹ and accepted in principle by DPW.

2. Presence of Systems for Monitoring Performance/Compliance, Frequency of Monitoring, and Corrective Actions.

In general, there are no regular reporting systems which flow from providers or sub-state units to the state level MR staff with the exception of DPW form 1503, which includes basic client intake information and is submitted to DPW by CWDs. This data is not used for monitoring. Otherwise, what data exists consists of annual or biennial activity reports from MR units of CWDs, DACs, and area CMH Boards contained in their plans/budget requests. There was no evidence that these data were used to monitor compliance with performance expectations. To date, these units of the state MR system do not appear to have been monitored in a systematic fashion at all, and therefore there has been no mechanism for the state to seek corrective actions within the span of its power to do so. State MR program staff freely acknowledged that state mechanisms for monitoring performance of sub-state units and providers were inadequate for system management and accountability, but felt that their current efforts to develop monitoring mechanisms would successfully address this problem at least with respect to county and provider performance. Monitoring systems which do exist consist of annual DPW and Health Department reviews of residential care providers for compliance with physical plant and program regulations. In the case of ICF/MRs, both Departments perform annual reviews; the Health Department cites deficiencies according to Federal requirements and obtains a correction plan from the facility which is used as a basis for review the following year. No cases

of de-licensure of an ICF/MR for failure to correct deficiencies was reported although county level staff and some advocacy groups alleged that inadequate facilities were allowed by the state to begin and continue operation in violation of the spirit if not the letter of various state regulations.

At the CWD level, Hennepin County requires monthly activity reports from its DACs and community (non-residential) programs; both of these types of programs have significant levels of county funding and MR staff consider it their responsibility to monitor the performance of these providers. The CWD does not monitor CRFs systematically because the county does not have a significant fiscal role in their operations and has no authority or staff to mandate changes in provider actions. This distinction is very clearly made by the county⁵² in its plan submissions to the state and represents a challenge to the current system organization which the county MR staff would like to have addressed.

Monitoring of CRFs with respect to individual service plans in the tri-county Zumbro Valley area has been informal and sporadic; the management information system being tested by Olmstead County is designed to systematize monitoring of provider adherence to individual service plans. At the time of the site visit, however, most of those interviewed stated that the real monitoring of CRFs and DACs for adherence to overall performance expectations was done by the local MARC chapter.

It may be concluded that the state and sub-state units in Minnesota's MR care system have been slow to develop and utilize monitoring systems outside of annual state-level licensure reviews of community facilities and services. How effective these reviews are in ensuring provider accountability

for performance is not clear; state-level monitors express the view that their monitoring is a teaching tool, and providers improve their practices as a result – therefore, de-licensure need not occur. This is disputed by some local officials and advocacy groups. In any case, the absence of systematic statewide monitoring systems to date has made it impossible for DPW to track what is going on in the total deinstitutionalization/community care effort.

As a result, DPW has been unable to provide information requested by the legislature or to hold the various system units accountable for performance. DPW/DMR have been able to get by thus far due to general legislative support for the system and the absence of reported abuses, there is evidence of growing restiveness with DPW's failure to be more accountable for the system, which may jeopardize future funding.

3. Performance of Effectiveness, Efficiency, and Impact Evaluations and Their Use for System Change.

Essentially, evaluations of overall DI/community-based care system effectiveness in meeting objectives, efficiency in resource utilization, and impact on individuals or the community began in Minnesota around 1975; even though some community residential care has been present in the state since the 60's, it was the rapid expansion of CRF's and collateral expansion of DAC's associated with the move to ICF/MR funding which clearly stimulated much evaluation activity in the state.

The major evaluations of the MR system produced thus far have been conducted by a variety of entities in addition to DPW/DMR. These include the Management Services Division of the State Department of Administration, which has continuing responsibility to conduct any such analyses as the Governor may request; the small legislative research staff which serves committees relevant to DI and community care; and the Minnesota Council for the Handicapped, a free-standing advocacy/research group created by the state legislature. In addition, the legislature recently created a Legislative Audit Commission with a Program Evaluation Division to serve as its ongoing research and evaluation arm, and D/community care evaluations may be expected from this source in the future.

Between 1975 and 1977, DPW/DDR conducted two evaluative studies of the MR service system: an analysis of inappropriate placements of MR persons in skilled and intermediate nursing facilities and ICF/MRs (Krantz),⁵³ and a major evaluation of system effectiveness and impact on clients (Bock).⁵⁴ The 1975 Krantz evaluation, using annual Health Department survey data and DPW questionnaire data collected especially for the study, concluded that inappropriate placements did not constitute a major problem, but that the placement process did require better management, including a requirement for improved behavioral assessment tools such as the MDPS and a clearer assignment of placement responsibility, and a management information system which could track client flow from one placement to another as well as monitoring individual developmental status and progress. In short, Krantz found that the achievement of system objectives for normalization and appropriate programming to promote maximum independence (the developmental model) was being hindered, though not defeated, by the absence of DPW/DDR management leadership.

Both, in a more comprehensive evaluation published in 1977, reached essentially these same conclusions; in addition, he determined that the continuum of care resources as set forth in the CAIR report was not being developed, but that the impact on clients of the CRFs was positive – i.e., there was low recidivism to state hospitals and a positive trend toward movement to more independent living settings where available. He recommended both the institution of management information systems at the state level and a policy of promoting the development of more semi-independent living programs. Together, these evaluations appear to have prompted DPW/DDR actions to develop management information systems and begin to work on the expansion of semi-independent living settings. The format action, when implemented, should lead to ongoing effectiveness evaluation capacity. What DPW/DDR has not yet provided for is evaluation of efficiency in the utilization of resources. Although the Department receives cost reports on CRFs for rate-setting purposes, these are not analyzed with a view toward efficient use of resources.

The Medicaid Cost Containment Study⁵⁵ published in late 1976, was requested by the Governor. This study constitutes the major efficiency evaluation of the D/community-based care effort and also analyses the potential impact on communities of state hospital closures. The authors of this detailed report concluded that community-based care per se was a more efficient utilization of state/local funds than state hospital care, based on the best data available. The report called on state policy-makers to move forward in stating DI policy but the legislature had not been able to reach firm conclusions at the time of the site visit.

The final major evaluation of the effectiveness of a component of the MR system noted by the study team was commissioned jointly by the Minnesota Council for the handicapped and the state Department of Education.⁵⁶ This study addressed the availability of appropriate education services for all handicapped children in the state, and concluded, among other things, that better coordination mechanisms between DPW and the Department of Education⁷⁶ were needed to ensure that deinstitutionalized school-aged children and adults received appropriate services. There was no evidence that either Department had attempted to respond to this finding and recommendation, however.

On balance, it may be concluded that Minnesota state government officials, within and outside of DPW, have addressed many of the major evaluation questions which should be asked of an MR service system. The quality of the evaluations is generally high. At the same time, DPW has signally failed to conduct efficiency (cost) evaluations or to build in an evaluation capacity for this purpose; this has generated legislative and gubernatorial mistrust and was one of several factors leading to the Department of Administration Medicaid cost study. In addition, DPW has been very slow to move on the recommendations produced by its own evaluations with respect to institution of a management system to enhance achievement of objectives. While the Department's extremely deliberate pace can be justified in part by the state of the art and a desire to pre-test the proposed system before mandating it, the problems which the evaluations found continue to hinder orderly system development.

4. Impact Evaluations Based on a Clear Definition of Services in Relation to Client Needs.

Evaluations of this type have not yet been conducted because DPW/ DMR currently lacks the data base with which to do so, even though there exists a definition of appropriate services for different client characteristics.

d. Needs Assessment

Minnesota's approach to this key element is discussed in terms of the study criteria below.

1. Clear Definition of Service/Setting Needs at Different Developmental Stages by Level of Disability

The CAIR Report which provides conceptual guidance to DPW/DDR regarding service needs set forth a typology of individual characteristics and the residential care setting(s) and training programs appropriate to each, as follows:⁵⁷

SKILL AREA / PHYSICAL CHARACTERISTICS	LEVEL	PROGRAMS
Severe medical condition	Chronic	Developmental Medical Program
Eating, dressing, personal hygiene, and communication skills	All "none" or "with help"	Family-Living Developmental Program Five-Day Board and Lodging Program Developmental Foster Program
Eating, dressing, personal hygiene, and communication skills	50% "independent" Age: 13+	Social-Vocational Training Program
Eating, dressing, personal hygiene, and communication skills	All "independent" Age: 16+	Supervised Apartment Training Program
Independent-living skills	100% "independent" or corrected for Age: 18+	Minimally Supervised Apartment Program

The measure of individual skill area/characteristics raised in the CAIR Report was the standardized Adaptive Behavior Scale, which is being supplanted by the Minnesota Developmental Programming System, (MDPS) scales developed by DPW staff and the University of Minnesota.⁵⁸ The objectives of the residential programs for individuals with different needs are defined as:

RESIDENTIAL PROGRAM	CHARACTERISTICS
Developmental/Medical Program	Life-sustaining service Self-care skill development
Family-living Developmental Program	
Five-day Board and Lodging Program	Self-care skill development
Developmental Foster Program	
Social-vocational Training Residence	
Supervised Apartment Training Program	Independent-living skill development
Minimally Supervised Apartment Program	

The support services to be associated with each type of program (DAC, Infant Stimulation, community recreation, special education, etc.) are spelled out in detail in the report.

While the appropriateness content of the CAIR needs definition is a matter for expert judgment, the manner in which the CAIR continuum addresses program needs by age, ability level, and physical status, is an excellent example of the conceptual approach which ideally would be applied to the needs assessment key element.

2. Statewide Data Gathering System to Measure Need as Defined

The state does not have in place any data gathering system for needs assessment, with respect to the currently secured or total potential population in need of services. When the MDPS goes into statewide use, the state will have the capacity to assess service needs for clients who come to the attention of CWDs.

At the time of the site visit, however, there was wide variation in county practice in determining individual need for services; numerous documents and many system participants all edged that individual client service needs were defined in practice more by the availability of services than by the developmental concepts expressed in the CAIR Report.

With respect to estimation of the total MR population and types of services needed, DPW/DDR has a simple formula devised from current use patterns and responses to the opening of new facilities for estimating gross CRF and state hospital bed needs and no method at all for estimating need for different types of residential programs within the CAIR continuum. The state and regional DD Councils generally use the conventional estimation formula of 3% incidence of retardation in the general population, with 11% of this group being sufficiently retarded to require residential care of some sort. The Zumbro Valley Area Board assesses need for services on the basis of surveys of providers regarding waiting lists, constituency group estimates, random sampling of the characteristics of the currently served, continuing contacts with physicians in the area, and manipulation of demographic variables to arrive at secure-based estimates of need. Hennepin County has performed a one-time major survey of the DI potential of residents of the state hospital in the area, but otherwise does not attempt to project needs; staff felt that such efforts were unreliable and yielded too little information in return for the effort expended.

The state's approach to aggregate needs assessment since the inception of the system has been forthrightly one of letting demand determine services – this is colloquially referred to as the "woodworks phenomenon," i.e., once resources are created, those who need them (in addition to MR persons known to CWDs and state hospitals) will "come out of the woodwork" to fill CFR slots. This approach has been accepted by the legislative until recently, but the Legislative Audit Commission was directed to develop more precise potential use estimates in 1977. It did so by examining the gross estimates and assumptions of DMR, the Home Appropriateness Committee, local ARCs, and regional DD councils to arrive at a synthetic

"best estimate" which did not break down need by type of service required for clients with different characteristics.⁵⁹ This approach to needs assessment while adequate in the early stages of system development, clearly does not promote orderly development of MR services in an equitable manner. A more sophisticated needs assessment methodology should develop once MDPS is in place.

In the absence of a statewide data system or method for assessing aggregate need, the remaining study criteria – ability to predict potential demands of specific high-risk populations and regular analysis of data – do not apply.

e. Resource Inventory

Minnesota's approach to maintaining an inventory of resources currently or potentially available to the MR/DD is described below in terms of the study criteria for this key element.

1. Statewide Resource Inventory Consistent with the Service-Based Needs Definition.

Neither DMR nor the state DD Council have a resource inventory method which can be related to the secure-base definition of need contained in the CAIR Report. Bock⁶⁰ had to ask the CFRs to choose one CAIR program description which most closely described each facility in order to determine the number of resources of each type. (Family hiring - Developmental and Social Vocational training comprised the vast majority).

Otherwise, resource inventories maintained at the state level consist of lists of facilities licensed under different rules (e.g., CFRS under DPW Rule 34, DACs under DPW Rule 38) or funded by separate appropriateness (work activity/sheltered workshops).

The Southeastern Regional DD Council, which works closely with the Zumbro Valley Area Board, does classify CRFs by the CAIR developmental objectives (life sustaining, self-care development, etc.)

The state DD Council in its 1978 Plan,⁶¹ provides a thorough discussion of mandated and potential service resources arrayed by state departments and agencies. This excellent compendium is not linked to the service-based definition of need but it is sufficiently clear to permit the reader to determine which resources might be appropriate to support different types of programs as defined by CAIR.

While the state's resource inventories of CRFs and MR support services appear to be reasonably up-to-date, it is indicative of DPW/DMRs overall weakness in system management information that a special survey had to be conducted to identify which DPW-funded CRFs offered which level of service.

2. Assessment of Expansion Capability and Other Resource Characteristics

Area Boards and CWDs can determine service expansion capability -- including vacancies and provider willingness and potential to expand services. -- through informal contacts with local DACs, CRFs, and other service providers. DPW and Health Department licensure teams should be able to obtain this information during annual recertifications, but there is no evidence that they do so. DPW does maintain lists of individual CRF capacity and the age of clients served, but Bock's special survey was required to determine individual CRF admission criteria (i.e., level of client functioning accepted by the facility).

At the area level, Zumbro Valley maintains an up-to-date file on CRF and other provider characteristics, Hennepin County only maintains information on DACs and community programs funded by the county; the Developmental Disabilities Task Force of the Metropolitan Council (a Twin-Cities general purpose consideration group) conducted a one-time resource inventory in 1976 which describes pertinent provider characteristics more fully, but there was no apparent intent to develop a system for continual updating.

The local MARC chapters and other advocacy/provider organizations provide information and referral services based on their own knowledge of local providers.

The approach to this key element in Minnesota is probably adequate for resource identification of individual clients at the local level, but the absence of complete information on provider characteristics at the state level constitutes a barrier systematic statewide planning for resource development.

3. Inclusion of Generic Resources Available to Clients

The Zumbro Valley Area/SE Minnesota DD Council, Meko Council and 1978 DD Council state plan resource incentives explicitly included generic (e.g., social service, community recreation, etc.) resources available to clients. The presentation type of information in these documents appears sufficient to direct providers and CWDs to appropriate resources.

4. Resource Inventory Data Reporting in Consistent Format; Routine Analysis by Responsible Unit

Although minimal reporting regarding number and type of resources is required of area Boards in their annual MR service plans, data are not reported in a consistent format and analyses of this information are not routinely performed at the state DPW level.

The Area Boards vary with respect to scope of analyses of resource inventory data, so it must be concluded that ongoing analysis of resource availability -- at least of the breadth and level of detail needed for optimal planning -- is not built into the state MR service system at any level.

f. Planning and Priority Setting

Performance of this key element in Minnesota is assessed below according to the study criteria.

1. Long-Range Strategic Plans and Priorities for System Development

As noted elsewhere in this Report, the State of Minnesota has not settled the issue of how much deinstitutionalization is to be pursued, at what pace, for which types of mentally retarded residents of state hospitals;

as a corollary, policies regarding admissions of new clients to the state institutions are not clear, beyond provisions for due process in commitment. This necessarily makes strategic planning and priority setting for the MR service system virtually impossible.

In addition, the state's long-standing adherence to the "woodwork theory" for system development undercuts strategic thinking; basically, the "woodwork" approach has led DPW/DDR officials to assume that whatever resources are created will be used as previously unserved clients come forth.

The CAIR Report does offer a broad view of what a complete community residential care system should look like, but DPW/DDR has not systematically built upon it to establish clear priorities for development of the different resources to serve clients at various levels of functioning.

In the defense of DMR, it must be recognized that this small staff group has been overwhelmingly preoccupied with the process of developing ICF/MR resources since the 1975 move to expand community residential care in general through this funding stream. The DMR Division Director was mindful of shortfalls in planning for the full continuum of care, but felt that an incremental approach was the best that could be done with the staff resources available.

Nevertheless, sub-state MR staff, advocacy/provider groups, and many others interviewed felt that the state's failure to engage in strategic planning and priority setting had gone on too long, and that the DMR should begin to take greater responsibility for guiding system development, a judgment with which the study team concurs.

The state DD Council 1978 Plan endorses the concept of strategic planning and priority setting, but does not set forth such a plan due to absence of data. In any case, the DD Council plan would not be binding on the state's MR service system.

2. Clear Criteria for Determining Short-term Priorities and Specific Milestones for Servicing the Priority Groups

Consistent with the lack of strategic planning and overall priority setting, DPW/DDR has not issued clear planning guidance to areas or counties regarding short-term priorities for services to be identified as sub-groups of the MR population.

Both Area Boards visited had developed their own priorities, with differing degrees of specificity, regarding groups to be secured in the near term. These priorities were based on each Area's analysis of the needs data available; the SE Minnesota DD Council Plan developed with participation of the Zumbro Valley Board, sets forth much more measurable milestones, in part because data gathering in this less populous area is much easier than for Hennepin County (Minneapolis). Another factor influencing the difference in specificity, however, is the attitude toward original data collection held by the respective Boards.

While MR staff in both areas strongly believe in planning based on good needs and resource data, the Hennepin County group is insistent that the state play a more supportive role in data collection while the Zumbro Valley staff has moved ahead on its own.

Because of factors such as these, the quality and measurability of short-term plans and priority objectives vary unsystematically across the state.

3. Development of Mechanisms to Secure Inclusion of MR/DP Priorities In Other Agency Plans

There has been very little activity of this nature at any level within the state MR community service system for reasons similar to those noted under the discussion of Service Coordination. The specific state statutory provisions for a broad array of supportive services for the mentally retarded in the community and in state hospitals reduces both the need and impetus for MR agency efforts to achieve priority for the MR population in CETA, Title XX, Community Development, and other planning

and priority setting processes.

The major state level cross-program priority for the MR achieved concerns Title XX, which is controlled by DPW. The Commission's office has specified that a proportion of Title XX funds will be set aside to reimburse counties for DAC support.

DMR was beginning to examine HUD rent subsidy programs, which are administered by sub-state sponsors under the Community Development Act, for their potential in supporting semi-independent and independent living for the MR, but no efforts had been made at the time of the site visit to gain priority for the MR under this housing program.

The Zumbro Valley Area MR Coordinator had investigated the possibility of obtaining priority for housing of the MR under the local CETA program, but had found CETA understandably reluctant because of the availability other state funds for training. He was also in the process of exploring the Sec. 8 rent subsidy program and the possibility of obtaining priority for the mentally handicapped in area housing plans.

4. Actual Use of Plans in Determining the Allocation of Resources

The relationship between CMH Area Board plans for CRFs and the allocation of resources is very slight because any provider who meets DPW Rule 34 and ICF/MR requirements can start operating with Title XIX ICF/MR funds, even though the residential program objectives and type of MR client to be served by the facility (e.g., self-care skill development for higher-functioning children) may not be the highest priority need expressed in an area plan. Under DPW Rule 185, there is provision for Area Boards to commit to DPW on the appropriateness of requests for DPW rule 34 certifications, but there had as yet been no cases in which an area had made a negative recommendation which was sustained by DPW. This appears to be of dubious legality in any event, as need for the facility is not a criterion for licensure under DPW Rule 34.

The alternative available to the CMH Area Boards is to make negative recommendations to area Health Systems Agencies, who have recommendatory denial authority for any health-related service.* One of the Areas visited reported having used this route, although the reason was more to prevent the operation of a CFR by an undersirable provider than to conform resource allocation to Area plans.

Clarification of the regulations to incorporate conformance to area plans or recommendations as a licensure requirement might be a more efficient way to relate resource allocation to planning; in any case, however, planners must actively encourage the development of desired resources in this purchase-of-service system if they are to obtain what is needed. There was some evidence that the Zumbro Valley CMH Area Board staff had done so with respect to CRFs, but Hennepin County had not. Performance of this aspect of resource allocation in relation to plans is probably uneven in the state.

With respect to DACs, the issue is almost moot because the state has had little more than a maintenance budget for the past two-three years. The critical decision rests with the county general purpose government inasmuch as hearing local matching funds are required. A county may directly operate a DAC, but few do so. The recruitment of providers for this service, if deemed needed, has not been a problem.

None of the plans reviewed referred specifically to the need for other supportive services, e.g. sheltered workshops, and resource allocations decisions for these appear to be made by the relevant state or local agency on an ad hoc basis.

It must be concluded that the state has lacked -- and may continue to lack -- appropriate mechanisms for relating resource allocation to plans, even where plans are sufficiently explicit to serve as guides. The effects of this on orderly system development are compounded by the fact that the state did not develop licensure rules and identify funds to be allocated for the more independent living end of the CAIR continuum of services.

* Final authority rests with the State Health Planning Agency.

g. Coordinated Funding

Minnesota's approach to performance of this complex key element is assessed in this section.

1. Specification of Levels of Funding Needed for MR Priorities, Based on Rational Criteria

The state MR community service system has encountered increasing legislative resistance to appropriate funds because DPW has been unable to assign priorities and adequately justify funding requests. Evidence of this concern is found in the State House of Representatives' creation in 1976 of a special committee on deinstitutionalization to hold hearings for the purpose of gathering information "...needed by the legislature to make judgments concerning care being provided the mentally ill, mentally retarded, and chemically dependent citizens of Minnesota and to equip itself with the data necessary for future legislative decision making regarding that case."⁶³

The committee held hearings on the cost and quality of care, and on the roles and responsibilities of various levels of governments in the provision of care. A summary of findings⁶⁴ presented to the committee by legislative staff is extremely negative with respect to the adequacy of cost data for MR services. It is also negative regarding the availability of information on the quality of care supported with Federal and state funds, and concludes that the overall MH/MR/CD system is incoherent.

This impatience with DPW's ability to justify funding requests is also reflected in the Governor's mandate to the Department of Administration to conduct the Medicaid Cost Containment Study cited elsewhere.

Legislative staff, advocacy/provider groups, and sub-state MR agency staff were in agreement that DPW had performed its justification role poorly, and had thus jeopardized MR program funding by the legislature. This widespread concern was not lost on DMR staff, whose efforts to develop

and implement a Management Information System and to conduct system evaluations were directed at providing the kind of data which could be used to make a clear case for funding to the legislature. What remained absent was any kind of performance evaluation of DACs. According to the Director of the Community Programs Division, a DD grant had been made to DPW for DAC evaluation, but was terminated before a full scale evaluation could take place. There was still little sense of urgency about evaluation of this program because of its popularity, even though there have been recent legislative cuts in appropriations requests. Since DAC services are central to the state's philosophy of normalization and requirements for individualized programming, continued failure to justify DACs to the legislature would have very serious consequences for the entire community care system.

2. Survey of the Full Range of Potential Federal, State, and Local Funding Sources and Development of Binding Agreements with Agencies Controlling These Funds

Just as inter-agency service coordination efforts beyond those prescribed in Minnesota law have been rare, the efforts to identify and obtain supplemental funding sources have been sporadic at best at all levels of the MR service system.

Minnesota was, however, the first state in the nation to see the potential of the ICF/MR funding stream to support group homes. DPW sought and obtained for the HGW Regional Office permission to pilot test the development of CRFs which would meet Federal ICF/MR requirements. The state and Regional Office determined that this use of ICF/MR funds was feasible even within the highly medically-oriented regulations, and the state made a commitment to use this funding source for the bulk of community care.

Even though the Medicaid Cost Control Study cited elsewhere found in favor of community-based ICF/MR care as opposed to state hospitals on a cost basis, there was a great concern among those interviewed that funds were being wasted because of overly stringent and inappropriate ICF/MR requirements.

Furthermore, the semi-independent and independent living components of the desired service continuum could not be funded through Title XIX, ICF/MR, and no one in the state had developed an alternative funding package. Existing apartment based programs were all found in the metropolitan counties which had the tax base to support such efforts. DMR staff were examining ways to fund the nine independent residential programs at the time of the site visit and had tentatively concluded that Supplemental Security Income (SSI) provided directly to the disabled would have to serve as the main source with other sources to be identified to cover staffing and support services.

The state's performance of this aspect of funding coordination has, thus, been a mixture of outstanding (albeit controversial) innovation and narrow focus.

3. Development and Implementation of Procedures for Ensuring Maximum Utilization of Individual Entitlements.

Responsibility for ensuring that MR individuals receive all financial and program benefits to which they are entitled by Federal and state law has been delegated to CWDs. Since DPE does not systematically monitor this aspect of CWD performance, there is no way to determine whether CWDs perform this function with uniform effectiveness.

4. Simple and Flexible Procedures for Packaging and Disbursing Multi Program Funds to Meet Client Needs

The "categorical" nature of the Minnesota community care system would seem to invite confusion in achieving the right mix of services needed for clients. However, even though it provides funds for its different components some through separate state and local appropriations, with support for CRFs, workshops, DACs, and special education going directly to the providers; there is little apparent need for "packaging" of funds for purposes of achieving simplicity and flexibility. The only problem noted by those interviewed with respect to the flow of funds to meet client needs in a timely manner was with respect to state Title XX reimbursements to counties for part of their share of DAC support. Reimbursements were reported to be slow, and some argued that the use of Title XX funds for

this purpose was duplicative and wasteful of resources since counties are responsible for matching state DAC funds from their own appropriations. However, since state appropriations have not matched county expenditures for DACs at the expected rate, it seems likely that DAC services would be cut back if Title XX were not used for their support.

The state's apparent success in avoiding undue gaps between system components may be due in part to the state DPW Rule 34 licensure process, in which the likelihood that DAC and other appropriate services will be available is taken into account in determining whether the potential provider will be able to comply with program requirements. At the same time, because so much of the system is funded through categorical state programs, there is reduce need to tap funds which are not earmarked for the MR and therefore reduced possibilities for conflicting eligibility requirements and funding cycles.

Such inappropriate placements as have been identified in evaluations cited earlier do not appear to be due to constraints on the level of funds or regulations concerning them. A probable exception is the case of adult MR persons who could live in supervised apartments but remain in ICF/MRs because funds are not available for less restrictive community settings.

5. Consistency of the Funding Package with MR/DP Agency Priorities

The state's reliance on Title XIX ICF/MR funding for CRFs and the general absence of funds for semi-independent living arrangements has not caused the state to provide a type of service which is inconsistent with its philosophy of normalization, however arguable the necessity for money ICF/MR requirements may be with respect to group homes for higher functioning children and adults. It has meant, as stated above, that when CMH Area priorities are for more semi-independent living programs, the funding sources in use will not support these priorities.

In brief, Minnesota's approach to funding has not yet taken the full continuum of care into account, but available funds appear to be adequately coordinated and have not prevented the system from adhering to its normalization objectives with the group home setting.

h. Resource Development

Minnesota's approach to this key element has been exemplary in many respects, as discussed below in relation to the study criteria.

1. Provision for Start-Up Financing of Small Group and Independent Living Settings.

Although there is a serious lack of funding for supervised apartment programs, the state has provided to some extent for start-up financing for group homes by including these costs retrospectively in provider rate structures under DPW Rule 52. Provider assistance representatives and group home providers visited did note that start-up financing was often difficult for small, independent providers who had no capital resources upon which to draw until reimbursed by DPW.

The rate provisions appear to deal well with start-up costs for group homes when several are under one non-profit or for-profit organization, but coverage of these costs is less adequate for independent providers, and many potentially excellent very small group home care providers may not be able to enter the system for lack of start-up support.

2. Adequacy of Rate Structures

DPW staff responsible for establishing Rule 52 per diem rates for providers felt that the rates were excessive, especially with respect to the number of daily hours which could be included in individual salaries. They also expressed the view that the ICF/MR requirements needlessly escalated costs, but Rule 52 permits all such costs to be included in the rate structure. Providers generally were satisfied with the rates they were able to obtain annually, although more frequent adjustments - particularly in the early years of operation - were seen as desirable. There is little question that ICF/MR rates are competitive with those for comparable care settings for other disability groups. Rates for foster care of the retarded in homes which do not seek ICF/MR status are considerably lower, however, and offer little incentive to families to provide this type of care, thus leaving a gap in the continuum of care envisioned in the CAIR Report.

3. Establishment and Implementation of Training and Technical Assistance to Develop Quality Resources

Minnesota's performance in this area has been outstanding in the recent past. Once the decision was made to expand CFR capacity through ICF/MR, the DMR obtained as grant from the Office of Rehabilitation Services within HGW to fund the Technical Assistance Project (TAP). The purpose of the TAP effort was to assist existing and potential group home providers in meeting state and federal requirements. The TAP staff and an ad hoc committee of MR professionals and advocates developed resource materials, held training seminars, and responded to individual inquiries from 1975 to 1977 when the grant expired. This effort received unanimous praise from those interviewed and it was seen as having been absolutely essential to the development of CRFs under the complex ICF/MR and state requirements.

Unfortunately, TAP was not made a permanent feature of DPW/DDR due to a DPW Commissioner's Office decision not to seek permanent staff and support from the legislature. It is questionable that additional CRFs will be able to meet requirements without lengthy delay in the absence of TAP.

There are no provisions for state funded training of personnel to care for the MR, but no problems were noted in finding trained supervisors and caregivers in the state. Minnesota has an extensive network of vocational technical schools which offer appropriate training for services to the MR; some multi-group home providers train their own staffs; AARM provides information about training materials; and some CMH Area Boards provide direct training. In addition, DPW Rule 34 licensure staff and Health Department ICR/MR and Quality Assurance survey teams engage in informal training of providers during the course of inspections. Providers reported these encounters as being helpful in meeting program requirements.

This aspect of resource development in Minnesota -- particularly the TAP effort -- has been very effective. It remains to be seen how well CRF resources can be developed in the future in the absence of TAP support.

4. Planned Growth Strategy for Resources Consistent With State MR/DP Priorities

There is no state level planned growth strategy for the CFR continuum of care, just as there is no statewide plan with priorities for development of different resources. While some Area Boards attempt to spell out the mix of resources which should be developed, no clear implementation strategies were noted. The Bock Report, cited earlier, makes it abundantly clear that types of CRFs have developed without reference to any researching plan for resource development, since "Family hiring -Developmental" and "Social Vocational Training" residential programs account for all but 14 of the 121 CRFs licensed under DPW Rule 34 in the state.

5. Establishment and Implementation of Mechanisms to Overcome State Hospital Employee and Community Resistance to Community Care

The Minnesota state legislature passed laws in 1973-75-77 which established state hospital employee rights to a job in another state hospital for a defined period of time if the hospital job is terminated due to deinstitutionalization; portability of pensions from the state fund to county government is also provided for. These actions, plus the state's indecisiveness about DI policy and the need for existing staff --even with a reduced hospital population -- to meet the higher ICF/MR staffing requirements have overtaken employee union opposition to DI.

The 1975 legislature passed a state zoning statute for CRFs which overrides local ordinances. There is still some community resistance to CRF, however, and organized efforts were being made to strike the statute at the time of the site visit. Providers visited had discussed their proposed program with neighborhoods and MARC engages in considerable community education efforts to break down resistance to the presence of retarded people in the community. While these efforts have enjoyed some services, the problem of community resistance still exists but has not been a critical barrier to resource development.

6. Reduction of Licensing Barriers to Providers While Maintaining Protection of Clients

Minnesota has not performed well with respect to this study criterion. The split in licensure authority between DPW and the Health Department, with DPW responsible for Rule 34 program licensure and the Health Department responsible for ICF/MR requirements and supervised hiring facility physical regulations, was a major source of dissatisfaction to provider groups and individuals contacted.

While the Health Department attempts to coordinate its inspections with those of the Fire Marshall and Building Code Inspectors, the multiple certifications required before a facility can open its doors is awesome. DPW Rule 34 is clearly a necessary developmental program complement to federal ICF/MR regulations, but the fact that two separate departments must be dealt with was generally described as "ludicrous," and much of TAPS effort had to go toward dealing with this complex licensure process.

The content of ICF/MR regulations when applied to group homes has been noted as a major issue in the state. The study team concurs with providers and advocates that many of the ICF/MR requirements are excessive, particularly for able-bodied higher functioning clients. The homes visited had managed to overcome the somewhat institutional physical characteristics promoted by the regulations through good design, but it is clearly wasteful and unnecessary to require, e.g., large bedrooms for children who are required by DPW Rule 34 to be in school all day and who play together in family rooms for much of the evening.

IV. Factors Affecting Minnesota's Performance of Key System Elements and Implications for Other States

A. Factors Affecting Performance

These factors have promoted more or less which effective performance of the key system elements, as measured by the study criteria, may be summarized as follows:

- Long-Standing Laissez-faire Attitude Toward Management Within DPW

Although components of Minnesota's MR community care system have been in place since the 60's, the former Commissioner of DPW did not create a unit to be responsible for DI and community care policy, planning, or operations. The community service system, although deinstitutionalized on the local level by law or administrative delegation of authority, still is subject to DPW supervision and leadership. The fact that it took an act of the legislature to create a MR Program Office to perform the leadership role is indicative of the Department's laissez-faire stance. Even though DPW has been headed by another Commissioner for the past several years, this stance does not seem to have changed. Efforts which were underway to improve performance with respect to system organization, service coordination at the point of delivery, and monitoring/evaluation, in particular, arose from external advocacy and legislative pressure and the interests of a few key DMR staff, rather than from any internal DPW pressures for better performance.

- Strong Advocacy and Provider Groups

The strength and effectiveness of MARC, AARM, MDACA, and others is working with the Governor and legislature has promoted system development and maintained basic support of policy-makers in the face of DPW management deficiencies over time. Without this strong coalition, it is highly unlikely that the legislature would have permitted community care system growth to the extent that it has even though there is essential argument among state policy makers on DI and normalization objectives.

- General Acceptance of the "Woodwork" Approach to System Development

Until the ICF/MR expansion caused more concern with costs, there has been no impetus from any source in the state to engage in systematic needs assessment, resource inventory, or planning/priority setting. The assumption that all community resources which were developed were sure to be fully utilized by an unknown pool of potential clients has

been borne out over the years, so that the "woodwork" approach seemed adequate to policy makers, MR agency administrators, and even the advocacy/provider coalition. The fact that this mode has not resulted in a true continuum of care consistent with concepts adopted by all system participants, coupled with alarm at ICF/MR costs, has led to pressures to engage in a more strategic planning and prioritizing mode with an improved data base for estimation of need and costs.

- Categorical Funding for MR System Components

The fact that Minnesota's system is based on a series of statutes, enacted over time, which provide categorical funding for most of the basic and support services needed by the MR community care system has reduced the need for system administrators to attempt to coordinate generic services or obtain funds and priorities for the MR across agency lines. While this has been a source of strength for the MR system in the past, it has become increasingly clear that DPW and Area Boards will have to reach out to other sources -- particularly for housing and support services for semi-independent living -- if the system is to achieve its objectives. Unfortunately, DPW/DDR lack a history of experience in working with other agencies to gain access to generic resources and this factor, plus the small number of staff within DMR and the Division of Community Programs has impeded progress along these lines.

- Openess to new Approaches to System Expansion and Creativity in Resource Development

Finally, while DPW/DDR can be faulted for a history of weak management and lack of initiative in exercising its clearly defined leadership role, the DMR was quick to take advantage of the potential of ICF/MR funding. Once the decision was made, DMR demonstrated considerable creativity in creating TAP and in developing Rule 52 so as to provide ample incentives to providers to offer CRF services.

B. Implications for Other States

Aspects of Minnesota's experience which seem to be particularly informative for other states contemplating deinstitutionalization and the creation or expansion of community-based care systems include the following:

- A commitment to the Development of Good Management Information Systems and Early Evaluation Should Accompany any Major Efforts at PI and Community Care System Expansion - In the words of one evaluator, the absence of good management information data and systematic client tracking capacity did not create a social disaster in Minnesota; nevertheless, it has hampered the orderly development of a continuum of care which the state is attempting to achieve and, of equal importance, has caused less of credibility with an unusually patient and supportive legislature. The development of the system has been jeopardized by DPWs failure to move more quickly to develop a sound data base and evaluation capacity with which to justify appropriations requests; this should have very high priority for the lead MR community care system agency in other states.

- Special Technical Assistance Is Essential for Rapid Resume Development

Whether a state uses ICF/MR or other means of financing community care, if rapid resource development is desired , a special team such as TAP is essential. Furthermore, even if the licensure process is much more streamlined than Minnesota's, the pool of potential providers who can meet basic requirements for physical safety and developmental programming without assistance will be small. The TAP effort demonstrates that good to excellent care resources can be developed quickly without chaos if there is sufficient attention to working with potential providers rather than waiting for them to discover what is needed for successful start-up and operations on their own.

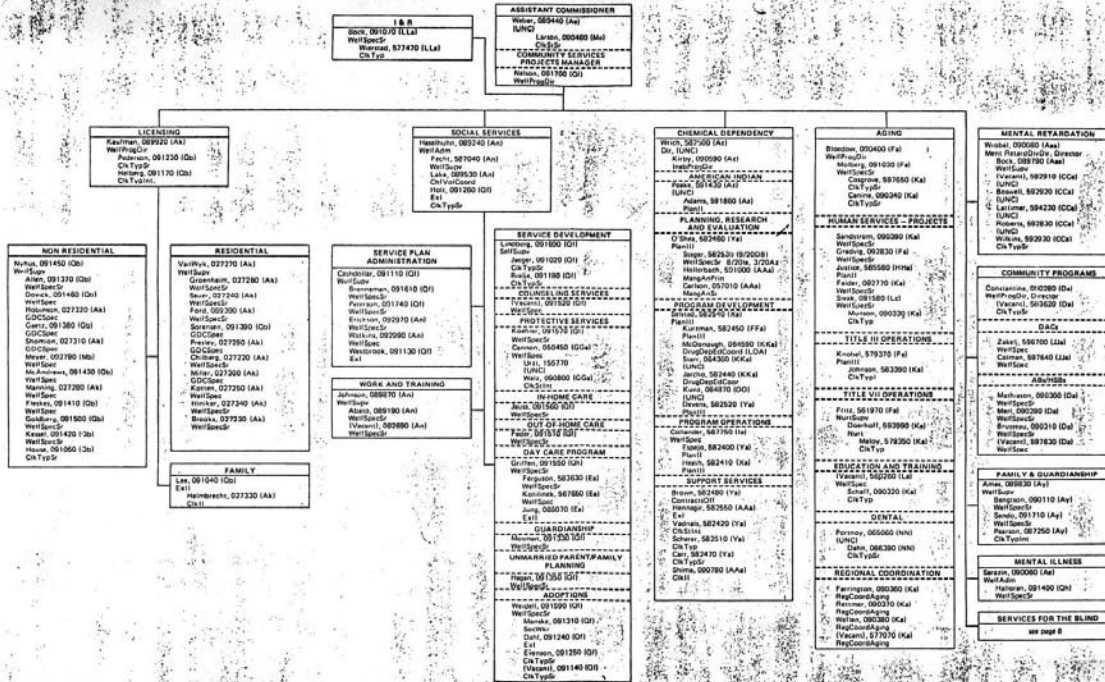
- Licensure/Certification Authority Should Be Unified in one Lead Agency with Provision for Denial Based on Need for the Service Proposed -

Notwithstanding the success of the TAP effort, too much of it had to be devoted to assisting providers through a needlessly complex licensure process as opposed to focusing more on program content. Primary licensure responsibility should be lodged in one agency at the state level or any other level which a state may choose to perform this function. Furthermore,

unless the state provides clearly for denial of licensure on basis of need in a purchase-of-service system, there will be inadequate means to ensure that resource development conforms to plans and priorities for the use of scarce resources.

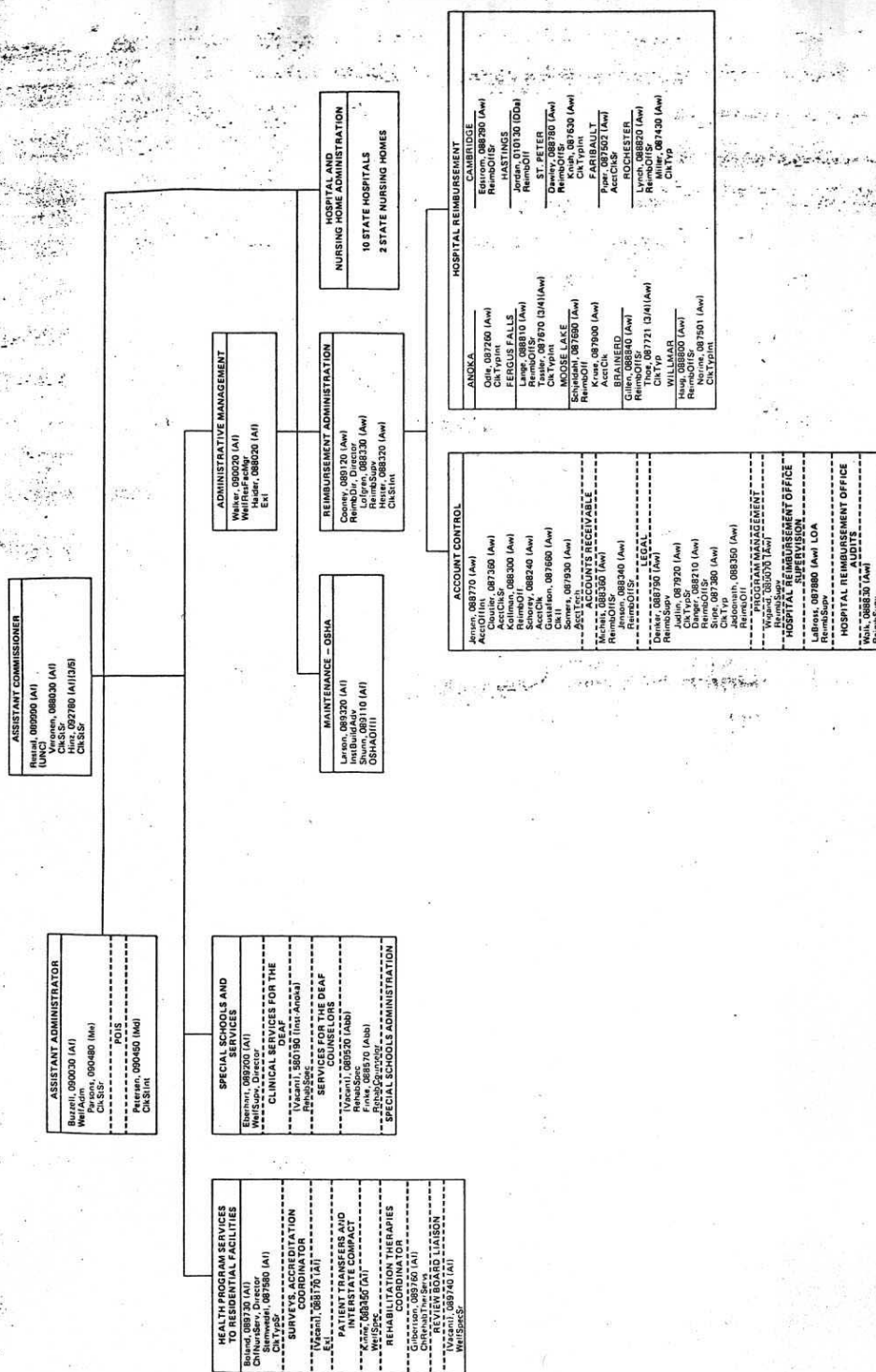
These are only a few of the lessons of the Minnesota experience in DI and Community care system development, but they do appear to have general applicability to any state undertaking major change to better meet the needs of its retarded citizens.

BUREAU OF COMMUNITY SERVICES





5



5 TV's

Mittels für Assistenten, Kommis und Angestellte Business-Children

GLOSSARY

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- CP - Cerebral Palsey
- DD - Developmental Disabilities or Developmentally Disabled
- MR - Mental Retardation or Mentally Retarded
- CB - Community Based
- DI - Deinstitutionalization
- CD - Chemically dependent (drugs/alcohol)
- DMHC - Community Mental Health Centers
- CMH Area Boards - 23 Community Mental Health Boards; boards with catchments areas of one or more counties; responsible for service planning for the mentally ill, MR, and CD population within their areas.
- MR Coordinator - Staff member of each Area Board with primary responsibility for all service matters affecting the MR population in the area.
- Human Resources
- Boards - 13 proposed boards representing a variety of human devices/ state agencies, with catchments areas corresponding to the state's 13 economic development regions. County participation is optional and only four boards have been formed.
- DPW - State Department of Public Welfare
- DMR - Division of Mental Retardation, also referred to as MR Program Office Agency within DPW Bureau of Community Services with primary responsibility for MR system planning and evaluation
- HSA - Health Systems Agency responsible for area health care planning and recommending approval or disapproval of new health care facilities and services. mandated by Federal Law (PL 93-641)
- DAC - Day Activity Center - a state program servicing primarily preschool and adult retarded and CP persons.
- Title XIX - The Medicaid Program authorized by the Social Security Act
- ICF/MR - Intermediate Care Facilities for the Mentally Retarded - Federal subsidized under Title XIX since issuance of regulations in 1974.
- SSI - Supplemental Security Income Program created under the Social Security Act to provide income for the aged, blind, and disabled.
- CWD - County Welfare Department
- Minnesota Housing Finance Agency - quasi-public lending agency with resource bond authority

Glossary Continued

- MARC - Minnesota Association for Retarded Citizens
- MDACA - Minnesota" Day Activity Center Association
- ARRM - Association of Residence for the Retarded in Minnesota
- CRF - Community Residential Facilities
- MDPS - Minnesota Developmental Programming System
- DVR - Division of Vocational Rehabilitation, within the State Department of Education
- DCP - Division of Community programs - Unit within the Bureau of Community Services, DPW, Responsible for MR program operations generally
- ISP - Individual Service Plan for MR clients required by DPW Rule 34 (the program licensure for community residential facilities)
- IPP - The Individual Program Plan which must be developed, consistent with the ISP, by day and residential facility staff.
- TAP - Technical Assistance Program. A three year project funded by HEW and administered by DMR to assist potential ICF/MR providers in meeting requirements.

FOOTNOTES

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- 1 July 1, 1975. Statistical Abstract of the United States, 1977, Table 10: Population - States 1960-1976. U.S. Department of Commerce, Bureau of the Census.
- 2 Ibid, Table 17: Metropolitan and Nonmetropolitan Area Population - States: 1960-1975.
- 3
- 4 City and County Data Book, 1972, Table 1.
- 5 Statistical Abstract of the United States, Op. Cit., Table 704: Personal Income Per Capita and Per Square Miles - States: 1960-1976.
- 6 Ibid.
- 7 Ibid, Table 477: State Tax Collections and Excise Taxes by Type of Tax - States: 1976.
- 8 Cf., "Comprehensive State Plan for Mentally Retarded and Developmentally Disabled in Minnesota," MR/DD Program Office, Comprehensive Program Bureau, Department of Public Welfare, St. Paul, Minnesota, March 1975.
- 9 The Twin Cities Area (Hennepin County) Commissioners also serve as CMH Area Board.
- 10 "Summary of Testimony Presented to House Committee on Deinstitutionalization," Kevin Kenney, House Research, September 20, 1976, p. 1. This definition is elaborated upon in "Community Alternatives to Institutional Reform (CAIR)," Minnesota State Planning Agency/Developmental Disabilities Program, January, 1975, p. 9.
- 11 Cf., CAIR, 1975 Plan; proposed Role & Function of State Institutions (position paper submitted by state MR Hospital Director to DPW), no date.
- 12 CAIR, Op. Cit.
- 13 Responsibility for licensing of ICF/MR facilities is split between DPW and the Department of Health.
- 14 As of August, 1978, the Minnesota Developmental Programming System (renamed the Minnesota Management Model for Deinstitutionalization) had been more fully developed but was still not in place, AMICUS, 3 No. 4, July/August 1978, p. 3.

- 15 373 F. Supp. 487, D. Minn. 1974.
- 16 State Institutions Informational Brochure 1977, Dept. of Public Welfare, St. Paul, Minnesota, p. 5.
- 17 Bock, Warren. An Analysis of Minnesota's Effort to Reintegrate its Mentally Retarded Citizens: A Study of Community Residential Facilities for the Mentally Retarded for Minnesota's Mental Retardation Program Division, Department of Public Welfare, St. Paul, Minnesota, 1977. According to Anderson, et al. (see below) the number of ICF-MRs had grown to 135 by November 1976. The difference in numbers of CRFs noted in the two reports may be due to closures of 16 facilities between 1974 and 1976 (Bock, *ibid.*, p. 51).
- 18 *Ibid*, p. 44.
- 19 Anderson, Lois, et al. Medical Cost Containment and Long Term Care in Minnesota. UI. State of Minnesota, Department of Administration, Office of Management Services Division, St. Paul, Minn., December 1976, p. 251.
- 20 *Ibid*.
- 21 *Ibid*.
- 22 Bock, *op cit.*, p. 50.
- 23 *Ibid*, p. 44.
- 24 *Ibid.*, p. 51.
- 25 Cf., Staff Paper: The Need for Residential Placements for the Mentally Retarded in Minnesota. Legislative Audit Commission Program Evaluation Division, March 24, 1977.
- 26 *Op Cit.*, pp. 250-251.
- 27 Krantz, Gordon. Mentally Retarded Persons Reported to be in Non-MR Placement in Minnesota: A Report to the Minnesota Department of Public Welfare. December 1975.
- 28 *Ibid*, Ch. 4, pp. 43-87.
- 29 Bock, W.H., et al., Minnesota Developmental Programming System- Behavioral Scales, St. Paul, University of Minnesota, 1975.
- 30 Cf., 1976-77 Status Report-Daytime Activity Center Grant-in-Aid, from Edward Constantine, Director, Community Programs Division, to Vera Likins.

- 31 Staff Paper: The Need for Residential Placements for the Mentally Retarded in Minnesota, op cit., p. 3.
- 32 Op Cit., Ch. 4, p. 51, passim.
- 33 Ibid., p. 62.
- 34 Developmental Disabilities; The First in a Series of Reports Analyzing Trends and Services in the Twin Cities Metropolitan Area. Developmental Disabilities Task Force of the Metropolitan Health Board, June 1977.
- 35 Op Cit., p. 286 passim.
- 36 Op Cit., passim.
- 37 DPW Rule 34. Standard for the Operation of Residential Facilities and Services for Persons Who Are Mentally Retarded, November 17, 1972, p. 7.
- 38 Op Cit., pp. iii-iv.
- 39 Op Cit., p. 9, 31 and passim.
- 40 Op. Cit., Ch. V.
- 41 Minnesota Statutes 1969, Chapter 252, as amended 1971.
- 42 Op Cit. P. 2.
- 43 Ibid., p. 4.
- 44 Minnesota Rule DPW 185--Community Mental Health Board and County Welfare on Human Service Board Responsibilities to Individuals Who Are Mentally Retarded, February 24, 1977.
- 45 Guidelines for Preparation of County Social Service Plan, Minnesota Department of Public Welfare, February 1977.
- 46 Agreement for the Purchase of Work Activity Center and Sheltered Workshop Services. Division of Social Services/DPW and Division of Vocational Rehabilitation/Department of Education, Oct. 6, 1976.
- 47 Proposal to the Developmental Disabilities Council from Ron Davis, Zumbro Valley Mental Health Center and Warren Bock, Mental Retardation Program Division, January 10, 1977, p. 10.
- 48 Bock, Op cit., p. 92.

- 49 MR/DD Program Office, op cit., p. 4.
- 50 Comments to Ardo Wrabel, Director, MR Program Office from Robin Reich, Hennepin County Department of Mental Health, Mental Retardation and Chemical Dependency, June 24, 1977.
- 51 Op cit., p. 16.
- 52 Proposed Service Plan for Mentally Retarded People in Hennepin County, Hennepin County MH/MR/CD Department, July, 1976, p. 48.
- 53 Mentally Retarded Persons Reported to be in Non-MR Residential Placement in Minnesota, Op cit.
- 54 An Analysis of Minnesota's Effort to Reintegrate its Mentally Retarded Citizens into the Community, Op cit.
- 55 Medicaid Cost Containment and Long Term Care in Minnesota, op cit.
- 56 Educational Management Services, Inc., A Study on the Status of Educational Services for the Handicapped in the State of Minnesota, December 1975.
- 57 CAIR, op cit., p. 18.
- 58 See Bock, Warren, and Weatherman, R.F., Minnesota Developmental Programming System: (1) Technical Manual, (2) User Manual, (3) Behavioral Scales, (4) Program Plan Packet, Minnesota Department of Public Welfare/University of Minnesota, Oct. 1976.
- 59 Legislative Audit Commission, Program Evaluation Division. Staff Paper: The Need for Residential Placements for the Mentally Retarded in Minnesota, March 24, 1977.
- 60 An Analysis of Minnesota's Effort to Reintegrate Its Mentally Retarded Citizens Into the Community, op cit., p. 45.
- 61 Minnesota Governor's Planning Council on Developmental Disabilities. Developmental Disabilities State Plan, F.Y. 1978, Ch. III.
- 62 Developmental Disabilities Task Force of the Metropolitan Health Board, Metropolitan Council of the Twin Cities Area. Directory of Services for Developmentally Disabled Persons, June, 1976.
- 63 Summary of Testimony Presented to House Committee on Deinstitutionalization, 1976.

64 Ibid.

65 DPW, DMR. Developing Community Alternatives: A Manual for Perspective
Developers, March 1976.